AIDS and the Historian

Proceedings of a Conference at the
National Institutes of Health
20-21 March 1989

Edited by

Victoria A. Harden and Guenter B. Risse

U.S. Department of Health and
Human Services
Public Health Service
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On the Cover

The popular California artist, David Lance Goines, created this poster to raise funds for the University of California Student Health Service at Berkeley. Reproduced with permission of the artist. Courtesy of the National Library of Medicine Collection.

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Preface

In May 1988, at the meeting of the American Association for the History of Medicine in New Orleans, a number of people interested in the history of AIDS organized an informal meeting to talk about common concerns. As a result, the AIDS History Group was founded with the goal of promoting coordination and cooperation among those writing about or collecting materials relating to AIDS. Victoria A. Harden of the National Institutes of Health (NIH) and Guenter B. Risse of the University of California, San Francisco, were elected as Co-Chairs of the group.

Two recommendations emerged from this organizational meeting. First was the periodic preparation and circulation of a list of members and their research interests to promote cooperative efforts and interchange of information. This list is maintained by Dr. Harden and is available upon request. The second recommendation was that a conference be held to evaluate the literature on AIDS, to discuss ways to apply historical standards to that literature, and to suggest research topics through which historians and other scholars might contribute to public debate.

Because the founding group of AIDS historians was small, the conference was conceived as a series of programmatic workshops. March 1989 was selected as the date for the conference, and, as word of the meeting spread, people from across the United States and abroad asked to participate. Clearly, there existed a strong current of interest in the history of AIDS throughout the medical and historical communities. Many people who could not attend the conference expressed interest in reading the proceedings; hence, this publication was prepared.

The goals of the conference, which was organized into four workshops, were to produce documentary strategies and recommendations for issues relating to AIDS that could benefit from historical inquiry. Speakers prepared papers to stimulate thinking about ways to approach the history of AIDS, each bringing to the conference unique interests and insights. Their presentations were designed as departure points for discussions in the small groups, from which recommendations have been distilled.

The conference organizers would like to acknowledge with gratitude the support of the following institutional sponsors: The

National Heart, Lung, and Blood Institute; the National Institute of Dental Research; the National Library of Medicine; the DeWitt Stetten, Jr. Museum of Medical Research at NIH; and the Department of the History of Health Sciences at the University of California, San Francisco, through a grant from the University of California President's Research Initiative in the Humanities. The views expressed by conference participants do not necessarily reflect those of the sponsoring organizations.

All AIDS historians are at the beginning of what promises to be an arduous, long, but thorough inquiry into this disease. It is hoped that these proceedings will generate productive discussion, serving as a catalyst for active involvement in this complex enterprise.

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Workshop 1

Before AIDS: An Overview of Previous U.S. Epidemics to Clarify the Administrative, Scientific, and Social Responses to Mass Disease

Introduction

Dr. Guenter B. Risse, the Co-Chair of this conference, is Professor and Chair of the Department of the History of Health Sciences at the University of California, San Francisco.

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Epidemics Before AIDS: A New Research Program

Guenter B. Risse, M.D., Ph.D.

For centuries, historians have documented the rise and fall of epidemic disease in virtually all corners of the globe. In most instances, their writings were meant to be chronologies of these dread events—eyewitness accounts of the horrors of sudden mortality combined with speculation about their causes. By the early 19th century, however, some of these accounts were written with the express purpose of linking epidemic disease with environmental phenomena—e.g., the weather, the seasons, earthquakes—following the traditional concept of an epidemic constitution proposed by Sydenham centuries earlier.[1] Works like Webster's *A Brief History of Epidemic and Pestilential Diseases*,[2] a Spanish work by Villalba,[3] Ozanam's *Histoire Médicale Générale et Particulière des Maladies Epidémiques*,[4] and Schnurrer's *Chronik der Seuchen*,[5] attempted to organize information obtained from earlier writers and other scattered sources. Their unidimensional, chronologically arranged accounts paid special attention to climatic and geographic factors which were at the time thought to be prominently implicated in epidemic outbreaks.

These authors also collected and presented curative and preventive methods which contemporary physicians and lay persons had previously employed and deemed successful in dealing with certain epidemics. Among these methods were traditional and well-orchestrated measures designed to preserve the public health. Physicians and other authorities involved in fatal epidemics were featured prominently in this historical genre, creating a perfect companion to the history of great physicians, a "history of great epidemics."

Just as writers of medical history justified their works by claiming that they possessed practical value for physicians, historians of epidemics likewise insisted that their longitudinal accounts were useful in understanding contemporary epidemic disease. This seemed especially true after the first outbreak of cholera in Europe and the onset of the famous contagionist/anti-contagionist debate.[6] For example, in an English translation of Hecker's *Epidemics of the Middle Ages*, the editor expressed the wish that epidemics would soon be subjected to Louis' numerical method "to arrive at the discovery of general laws."[7]

By the end of the 19th century, August Hirsch's *Handbook of Geographical and Historical Pathology*,[8] as well as Creighton's own *A History of Epidemics in Britain*,[9] contained a vigorous defense of the miasmatic, anticontagionist position, stressing the importance of climate and geography in the genesis of mass disease. Moreover, Creighton introduced an additional neo-Darwinian scaffolding for his chronologically arranged analysis. He insisted that as environmental conditions shifted, a gradual evolutionary process operated, whereby one epidemic disease superseded another. Thus, for example, leprosy gave way to plague followed by typhus, then smallpox to measles, and so on.[10]

Creighton's idea that an epidemic disease had a life of its own directed not only against the evolving bacteriological determinism (he was opposed to the germ theory of disease) but also against the ahistorical character of such a notion.[11] Creighton conceived the historical ebb and flow of epidemic disease as reflecting the dynamics of life itself on earth, always adapting to evolutionary pressures. Although with a somewhat more metaphorical meaning, the "birth" and "death" of a disease model continues to survive in the literature.[12] Often submerged within broader ecological frameworks, this dynamic history of epidemics opposes unchanging, "Platonic" categories of epidemic disease that are traced back historically as if they were natural and permanent fixtures of our past and present.[13]

It was perhaps predictable that Creighton's idea of an evolutionary history and geography of epidemic disease flourished among health professionals during the early 20th century. With the help of maps and statistics, historians and physicians conducted longitudinal studies to delineate past epidemiological patterns and further understanding of specific diseases. The specter of World War I prompted the Carnegie Foundation to encourage studies on the causes and effects of war, including a 1916 monograph by Prinzing that highlighted the outbreak of epidemics among civilians in war-torn areas.[14]

In the 1920's, the League of Nations in Geneva issued a number of reports from the Epidemic Commission, combining both historical and contemporary perspectives. By 1931, the International Society for Geographical Pathology was established, also in Geneva, and in 1934, one of its founding members, Folke Henschen, published a widely read book, *The History and Geography of Diseases.*[15] Greater attention to tropical medicine in turn led to publication of selected histories of disease[16] and monographs on single diseases, such as Carter's *Yellow Fever* in 1931[17] and Celli's *Malaria in the Roman Campagna.*[18] Finally, Gill's *The Genesis of Epidemics*[19] exemplifies the intention of all these writers: to describe the historical behavior of certain epidemic diseases, their "natural history," as it were, so as to facilitate their diagnosis and control.

World War II merely accelerated this historiographical trend, as physicians became interested in the epidemic diseases awaiting American soldiers at battlefronts around the world. Simmonds' *Global Epidemiology*[20] was a product of the Surgeon General's Medical Intelligence Division, and the Germans had their own *World Atlas of Epidemic Diseases.*[21] Scott's *History and Geography of Tropical Medicine*[22] in turn reviewed a number of tropical diseases identified in the 20th century.

By the 1960's, Erwin Ackerkneckt's publication on the history and geography of epidemic disease spoke to the need of contemporary physicians to understand their past, especially those who worked in "so-called under-developed areas still exposed to high burdens of sickness."[23] Ackerkneckt believed that "rapid changes in the incidence patterns of diseases brought about by social evolution and modern therapeutic methods" made such a historical perspective absolutely necessary.[24] In recent decades, the medical history of epidemics has broadened to include, equally, biological and social developments. Grmek's concept of "pathocoenosis"[25] and the more recent ecology of disease are multidimensional models which attempt to study the dynamic, but complex, relationship between biological and social factors in the genesis, evolution, and retreat of epidemic disease.[26]

Ackerknecht's study of malaria in the upper Mississippi Valley was an early example of such a "total" history, carefully examining environmental, geographical, political, cultural, biological, and medical aspects inextricably bound together.[27] A similar study concerning the existence of malaria in 18th-century

Scotland and studies on the ecology of plague in Renaissance Europe are forthcoming.[28] Such work can no longer be characterized as simple narration of epidemic events, but, rather, is the careful integration of data obtained from multiple sources, from weather charts to parish reports, financial records to census figures, medical texts to newspaper articles. Most of the webs of causality discovered by Ackerknecht, Norris, myself, and others unavoidably require detailed analysis of social structures and cultural context.

Although most inquiries into disease ecology have focused on discrete epidemic episodes (the "micro view"), one author boldly employed a "macro lens" to focus on the effects of epidemic disease on the whole course of human history. William H. McNeill, in his 1976 book, *Plagues and Peoples*, scrutinized the record of world history for major political turning points and cultural shifts that could possibly have been decisively influenced by mass disease.[29] While frequently conjectural and biologically deterministic, McNeill's analysis, characterized as the view from 40,000 feet up, nevertheless encouraged further longitudinal and vertical studies of past epidemics. Even historians not previously interested in health were encouraged to include such issues in their reconstructions, thereby exposing in much greater detail the complex social responses to epidemic disease.

Social historians, for their part, now took advantage of epidemic episodes to obtain valuable information about society's structures, organization, and prevailing cultural values. This approach was first successfully employed in Briggs'[30] and Rosenberg's[31] studies of 19th-century epidemics of cholera. Combining medical sources and popular literature, Rosenberg concentrated on three distinct cholera epidemics in New York, exposing the conflicting nature of the social responses and the problems of institutions confronted with such crises. A student of Ackerkneckt, Rosenberg acknowledged the influence of his teacher's ecological approach.

For some time, however, Rosenberg's approach was not widely imitated. As Slack observed in 1974, social historians were reluctant to enter the world of disease, being painfully aware of the problems inherent in finding and interpreting the evidence, especially when lacking knowledge about biological and medical subjects.[32] There were other dangers: inexperienced authors tended to overemphasize the influence of disease on documented events. Claims that malaria had caused the decline of Greek civilization;[33] lead poisoning the fall of the Roman Empire;[34] and plague the collapse of Europe's feudal system[35] were, of course, harmful oversimplifications.

Nevertheless, the social history of epidemics survived and gradually gained momentum,[36] fueled in part by issues debated in historical demography, especially the 18th-century population explosion in Europe. When and where did it occur? How were population increases related to living standards (notably nutrition), and mortality (from epidemic "crises")? Spurred by McKeown's 1976 book, *The Modern Rise of Population*,[37] historians set out to study the complex interrelationships of fertility and nutrition, immunity and disease. Thus, roused by the 1976 "macro" studies of the two "Big Mcs," McNeill and McKeown, social historians went to work. Slack had accurately predicted that the "historian's approach to disease is becoming very like that of the social anthropologist in his concern to relate it to the total society in which it occurred."[38] The past decade and a half has indeed witnessed an impressive number of such studies: Cipolla[39] and Carmichael[40] on the plague in Italy; Morris,[41] Pelling,[42] Durey,[43] and Delaporte[44] on cholera; Slack[45] on plague; and Brandt[46] on syphilis.

The latest entry in this field is Evans' *Death in Hamburg*,[47] a detailed account of the 1892 cholera epidemic which afflicted that great German port city. Evans not only narrates the disaster and explains the measures employed to contain the epidemic, he reaches back to the mid-19th century and examines the relevant political and social contexts that favored the epidemic outbreak. His tridimensional model includes discussions about the general issues of modern urbanization: population growth, industrialization, public hygiene, class conflict and political organization, and medical and popular views of disease. An analysis of the values driving all social responses is also included. As Evans himself acknowledges, the richness of his sources allowed him actually to reconstruct what he calls the "inner life" of a great German city. For this purpose, the author was forced to cut across a number of disciplinary boundaries, from urban and political history to the geography of disease, from demography to medical history, from history of epidemics to nutrition and social welfare.[48]

Evans' new book is truly part of what Slack recently characterized as a "flourishing genre of sociological disaster studies," sudden events which test the contemporary structure of society, its resourcefulness, knowledge, and value systems.[49] As Rosenberg has repeatedly argued, epidemics are useful sampling devices that allow a cross-sectional perspective. How people interpret and react to epidemic crises reveals a great deal about their intellectual backgrounds, their values and beliefs, and their resolve and adaptability to challenges.[50]

Three years ago, some leading American historians of medicine acknowledged publicly that they had a responsibility to contribute to a better understanding of the newest epidemic disease: AIDS. Since then, several publications and formation of an AIDS History Group have demonstrated a scholarly commitment to illuminate and explain aspects of this disease through comparative studies of previous mass outbreaks.[51] It is no surprise, then, that medical and social histories of epidemics have largely merged in the 1980's, both intent on providing broader perspectives.

While certain aspects of the AIDS epidemic are unique, given the nature of the biological encounter and the sociocultural context of late 20th-century America, AIDS shares a number of traditional patterns of response with previous epidemics, especially those of a sexually transmitted nature and of a chronic and wasting variety.[52] Quickly presented "panoramic" comparisons between AIDS and previous epidemics, however, often created by the media, are not helpful. We must continue to work on specific epidemic episodes to achieve well-rounded and detailed reconstructions. The sources necessary for such studies include government papers, public posters, medical texts, daily newspapers, epidemiological reports, private letters, and oral histories. Informed by present concerns, our work must be thorough and detailed. While destroying thousands of lives, AIDS has paradoxically become a boon to historians. Let then our work in the history of epidemics go forward, and its fruits enlighten debates concerning our most recent and deadly plague.

Notes

1. *See* "On Epidemic Diseases," in *The Works of Thomas Sydenham* (translated from the Latin by R. G. Latham). 2 vols. London: The Sydenham Society, vol. I, pp. 32–41; 1847.

2. Noah Webster. *A Brief History of Epidemic and Pestilential Diseases.* 2 vols. Hartford, CT: Hudson & Goodwin, 1799.

3. Joaquin de Villalba. *Epidemiologia Española o Historia Cronologica de las Pestes, Contagios, Epidemias y Epizootias.* Madrid: F. Villalpando, 1803 (see especially the introduction, pp. x–xvi).

4. Jean A. F. Ozanam. *Histoire Médicale Générale et Particulière, des Maladies Epidémiques, Contagieuses et Epizootiques.* 4 vols. Paris: 1835.

5. Friedrich Schnurrer. *Chronik der Seuchen.* 2 vols. Tübingen: C. F. Osiander, 1825.

6. *See* E. H. Ackerkneckt, "Anticontagionism Between 1821 and 1867." *Bulletin of the History of Medicine* 22 (1948): 562–593.

7. J. F. C. Hecker. *The Epidemics of the Middle Ages* (translated from the German by B. G. Babington). London: The Sydenham Society, 1844. *See* general preface, p. vi. [Hecker believed that the previous generation had failed to leave proper records about epidemics. "History alone can fill it up; she alone can give to the doctrine of diseases that importance without which its application is limited to occurrences of the moment." (p. xii).]

8. August Hirsch. *Handbook of Geographical and Historical Pathology* (translated from the German by C. Creighton). 3 vols. London: The New Sydenham Society, 1883-1886. Another early work is Edward Bascome's *A History of Epidemic Pestilences from the Earliest Ages* (1495 BC–1848), London: J. Churchill, 1851.

9. Charles Creighton. *A History of Epidemics in Britain.* 2 vols. Cambridge: Cambridge University Press, 1891–1894. For a lengthy critique and review of this work, see R. S. Roberts, "Epidemics and Social History." *Medical History* 12 (1968): 305-316.

10. *See* D. E. C. Eversley, "Epidemiology as Social History," in a reprint edition of Charles Creighton's *A History of Epidemics in Britain.* London: F. Cass 1 (1965); 3–39.

11. For more information on Creighton, see E. A. Underwood, "Charles Creighton, M.A., M.D. (1847-1927): Scholar, Historian and Epidemiologist." *Proceedings of the Royal Society of Medicine.* 41 (1948): 869–76.

12. For a recent example, see R. P. Hudson, "How Diseases Birth and Die." *Transactions and Studies of the College of Physicians of Philadelphia* 45 (1977): 18–27.

13. This dynamic notion is succinctly conveyed by R. J. Dubos, "The Evolution of Infectious Diseases in the Course of History." *Canadian Medical Association Journal* 79 (1958): 445–50.

14. Friedrich Prinzing. *Epidemics Resulting From Wars.* Oxford: Clarendon Press, 1916 (see introduction, pp. 1–3).

15. Folke Henschen. *The History and Geography of Diseases* (translated from the Swedish by J. Tate). New York: Delacorte Press, 1962.

16. Henry Harold Scott. *Some Notable Epidemics.* London: W. Arnold, 1934, and Major Greenwood, *Epidemic and Crowd Diseases: An Introduction*, New York: Macmillan Co., 1935.

17. Henry R. Carter. *Yellow Fever: An Epidemiological and Historical Study of Its Place of Origin.* Baltimore: Williams & Wilkins Co., 1931. (Carter had been an Assistant Surgeon General of the United States Public Health Service.)

18. Angelo Celli. *The History of Malaria in the Roman Campagna, From Ancient Times*, edited and enlarged by A. Celli-Fraentzel. London: J. Bale & Sons and Danielson, 1933.

19. Clifford A. Gill. *The Genesis of Epidemics and the Natural History of Disease; An Introduction to the Science of Epidemiology*, based upon the study of epidemics of malaria, influenza, and plague. London: Bailliere, Tindall & Cox, 1928.

20. James S. Simmons. *Global Epidemiology.* Philadelphia: Lippincott, 1944.

21. Ernst Rodenwaldt, ed. *Welt-Seuchen-Atlas, Weltatlas der Seuchenverbreitung und Seuchenbewegung.* 3 vols. Hamburg: Falk, 1956. (This work was translated into English and re-edited by Richard E. Rodenwaldt, *World Atlas of Epidemic Disease*, Washington, D.C., Bureau of Medicine and Surgery, Navy Department, 1952–1961.)

22. Henry Harold Scott. *A History and Geography of Tropical Medicine*. Baltimore: Williams & Wilkins, 1939.

23. Erwin H. Ackerknecht. *History and Geography of the Most Important Diseases*. New York: Hafner, 1965, p. x.

24. *Ibid.*

25. M. D. Grmek. "Préliminaires d'une Etude Historique des Maladies." *Annales (Economies, Sociétés, Civilizations)* 24 (1969): 1473–1483. The author's concept is explained further in "The Conceptualization of Pathological Events," in his book *Diseases in the Ancient World*, translated from the French by M. and L. Muellner. Baltimore: John Hopkins University Press, 1989, pp. 1–4.

26. The literature is quite extensive. For an overview, see Macfarlane Burnet and David O. White. "The Ecological Point of View." *Natural History of Infectious Disease*. 4th ed., London: Cambridge University Press, 1974, pp. 1-21, and Frank Fenner, "The Effects of Changing Social Organization on the Infectious Diseases of Man," in *The Impact of Civilization on the Biology of Man*, edited by S. V. Boyden. Toronto: Toronto University Press, 1970, pp. 48–76. For more recent work, consult R. M. Anderson and R. M. May, eds., *Population Biology of Infectious Diseases*. New York: Springer, 1982, and a provocative article by J. A. Miller, "Diseases for Our Future: Global Ecology and Emerging Viruses." *BioScience* 39 (1989): 509–517.

27. Erwin H. Ackerknecht. "Malaria in the Upper Mississippi Valley, 1760-1900." Supplement to the *Bulletin of the History of Medicine* 4 (1945).

28. Guenter B. Risse. "Ague in Eighteenth-Century Scotland: The Ecology of a Disease," in *William Cullen and the World of Eighteenth-Century Medicine* (forthcoming). (The ecology of Renaissance plague is being investigated by John Norris.)

29. William H. McNeill. *Plagues and Peoples*. Garden City, NY: Anchor Press-Doubleday, 1976. For a summary, see, by the same author, "Disease in History." *Social Science and Medicine* 12B (1978): 79–84.

30. A. Briggs. "Cholera and Society in the Nineteenth Century." *Past & Present* 19 (1961): 76–96.

31. Charles E. Rosenberg. *The Cholera Years: The United States in 1932, 1849 and 1866.* Chicago: University of Chicago Press, 1962. See, also by the same author, "Cholera in Nineteenth-Century Europe: A Tool for Social and Economic Analysis." *Comparative Studies of Society & History* 8 (1965/66): 452–463.

32. Paul Slack. "Disease and the Social Historian." *Times Literary Supplement*, March 8, 1974, pp. 23–24.

33. Celli had made such a claim. For a recent view, see Grmek, *Diseases*, especially ch. 10, pp. 265–283.

34. S. C. Gilfillan. "Lead Poisoning and the Fall of Rome." *Journal of Occupational Medicine* 7 (1965): 53–60. For an update, consult J. O. Nriagu. "Saturnine Gout among Roman Aristocrats: Did Lead Poisoning Contribute to the Fall of Rome?" *New England Journal of Medicine* 308 (1983): 660–663.

35. William M. Bowsky, ed. *The Black Death, a Turning Point in History?* Huntington, NY: Krieger, 1978.

36. See, for example, G. N. Grob. "The Social History of Medicine and Disease in America: Problems and Possibilities." *Journal of Social History* 10 (1977): 392–409.

37. Thomas McKeown. *The Modern Rise of Population.* New York and San Francisco: Academic Press, 1976.

38. Paul Slack. "Disease and the Social Historian," p. 24.

39. Carlo Cipolla. *Cristofano and the Plague.* Berkeley: University of California Press, 1973, and *Faith, Reason, and the Plague in Seventeenth-Century Tuscany.* Ithaca: Cornell University Press, 1979.

40. Ann G. Carmichael. *Plague and the Poor in Renaissance Florence.* Cambridge: Cambridge University Press, 1986.

41. Robert J. Morris. *Cholera 1832: The Social Response to an Epidemic.* London: Croom Helm, 1976.

42. Margaret Pelling. *Cholera, Fever, and English Medicine, 1825-1865.* Oxford: Oxford University Press, 1978.

43. M. Durey. *The Return of the Plague: British Society and the Cholera, 1831–2.* Dublin: Gill and Macmillan, 1979.

44. François Delaporte. *Disease and Civilization. The Cholera in Paris, 1832* (translated from the French by A. Goldhammer). Cambridge: MIT Press, 1986.

45. Paul Slack. *The Impact of Plague in Tudor and Stuart England.* London: Routledge & K. Paul, 1985.

46. Allan M. Brandt. *No Magic Bullet: The Social History of Venereal Disease in the United States Since 1880.* Oxford: Oxford University Press, 1985.

47. Richard J. Evans. *Death in Hamburg: Society and Politics in the Cholera Years, 1830-1910.* Oxford: Clarendon Press, 1987.

48. For a summary of the author's approach, see R. J. Evans. "Epidemics and Revolutions: Cholera in Nineteenth-Century Europe." *Past & Present* 120 (1988): 123–46.

49. Paul Slack. "The Functions of Disaster." In *The Impact of Plague in Tudor and Stuart England*, pp. 4–7. See also Jacques Ruffle, *Les Epidémies dans l'Histoire de l'Homme: Essai d'Anthropologie Médicale*. Paris: Flammarion, 1984.

50. C. Rosenberg. "What is an Epidemic? AIDS in Historical Perspective," *Daedalus* 118 (1989): 1–17. By the same author, consult "Disease in History: Frames and Framers." *Milbank Quarterly* 67 (1989), suppl. 1, 1–15.

51. For example, see Elizabeth Fee and Daniel M. Fox, eds. *AIDS: The Burdens of History.* Berkeley: University of California Press, 1988.

52. A. M. Brandt. "The Syphilis Epidemic and Its Relation to AIDS." *Science* 239 (1988): 275–380.

Discussion

Speaker: We have time for questions.

Participant: We each come here from different training and different domains of relevance. Hence, it seems that our writing will have different emphases and follow different methodologies. Do you think that the history of AIDS could lead to the creation of multidisciplinary endeavors, centers, and programs of study? It seems that funding mechanisms are actually making it harder to bring together disparate groups such as biomedical and psychosocial researchers.

Speaker: I think that future research will be accomplished within existing frameworks, rather than by creating new ones. Few people, however, can do a study such as the one Dr. Evans undertook. His monumental opus is 900 pages long and took him more than 10 years to research and write. Obviously, it would be much more efficient for work such as this to be done collaboratively, but there is also the danger that joint projects tend to homogenize particular viewpoints. Perhaps a multidisciplinary approach could be launched with special funding, within certain institutions such as Humanities Research Centers. Collaboration could be very valuable but must be carefully planned in advance.

There are always two agendas to any workshop. One is to do some brainstorming and come up with new ideas; the other is to get to know people. Workshops can have important social and professional consequences if participants have time to get to know each other. Meetings often lead to relationships that transcend the institutional and geographic boundaries and bring about new contacts and future collaboration.

Popular and Public Health Responses to Tuberculosis in America After 1870

David F. Musto, M.D.

My interest has been in the area of drugs, which is related to AIDS in an intimate way, but today I am going to talk about the tuberculosis scourge that affected the Western world. I am especially interested in tuberculosis in the late 19th and early 20th centuries, because some of the issues which are so hotly debated now were also addressed at that time. It is as if AIDS turned a spotlight onto dusty records, reprints, and manuscripts which had been settled once and forever in a quiet part of the library. Now, suddenly, they seem to belong on the new bookshelf.

As the AIDS crisis has deepened, there have been many calls for traditional public health measures. These include mandatory testing and reporting, contact tracing, and isolation or quarantine. Countering these suggestions are protests that such measures will be counterproductive and that they are unnecessary invasions of privacy. On the one side are contemporary concerns for individual rights, and on the other are apparently well-established methods to confront and defeat a communicable disease. It has taken us a long time to learn the catechism of proper public health measures to control a communicable disease, yet people who advocate them for AIDS are told, "No, that's not the way we're going to do it." It reminds me of the current beliefs about alcohol. It took us decades to learn that alcoholism is a disease, yet the latest fashion is to say that alcoholism is not a disease. This is very confusing to people.

The dispute over public health measures against AIDS has reopened for historians the conventional history of chronic communicable diseases such as tuberculosis. As taught in the medical schools, the tuberculosis scourge, at one time the leading cause of death in the United States, was brought under control and all but vanquished by early detection, isolation, and the creation of sanitoria around the world. Depending on the era in which the success was being described, tuberculosis responded well to treatment by bed rest, high altitudes, cold air, collapsed lungs, or antibiotics.

How accurate is the link between public health measures and the success of the anti-tuberculosis campaign? A recent study of British tuberculosis rates concluded that the decline began in the mid-19th century, continued steadily through the mid-20th century, and continued at this steady rate "irrespective of medical or political interventions."[1] This is an astounding conclusion. If true, it means that the 20th-century efforts to remove open cases of tuberculosis from workplaces or from families did not hasten the decline of consumption any faster than the 19th-century complacency and resignation that attributed tuberculosis to heredity and fate. It means that the widespread testing for exposure to tuberculosis and subsequent treatment, or contact tracing, did not affect the rate of decline of death from tuberculosis. This is hard to believe if we accept the traditional history of the antituberculosis campaigns. If the link between traditional public health methods and the decline of tuberculosis is uncertain or weak, however, we historians should examine carefully and critically the path from medical research to those public health recommendations for curbing disease which so profoundly affect individual freedom and political processes, such as testing and involuntary isolation.

When you read of recommendations for Draconian antituberculosis measures, such as the proposals by Dr. Herman Biggs for "administrative control" of the disease, you find a chart or graph showing the success in the battle to date. How can you argue with the recommendations when the graph shows that success is being accomplished through measures already taken?

When I was Assistant to the Director of NIMH, a graph would be brought out whenever there was an important announcement to be made. This graph showed an arrow pointing down, then to the right. It purportedly showed that the number of hospitalized mental patients was continually going down. It was often in evidence when NIMH made a new recommendation about mental health for the American people. Of course, we now know that the NIMH graph concealed many complexities. Herman Biggs' assertions about tuberculosis did also.

Another side of the mental health effort is even more relevant to tuberculosis. When I was working on the history of the community mental health center movement, I was extremely interested to read that Public Health Service officials such as Dr. Robert Felix, who became the first Director of NIMH, saw the anti-tuberculosis campaign as a model for the attack on mental illness: door-to-door, community-wide detection of the emotionally disturbed, ideally in the incipient stages, perhaps before they realized there was anything wrong. This could lead to a massive assault on mental illness, and Dr. Felix published on this subject shortly after World War II, at a time when faith in the mental health movement and in techniques to cure mental illness was reaching a peak. The hope was that such an attack on mental health could follow the success of the tuberculosis model—that if we could only adopt its best features, the attack on mental illness would go well. In the early stages of the mental health center movement, there were extensive discussions of, and plans to do house-by-house studies in catchment areas to determine who was fragile and who needed help. The methods advocated for tuberculosis had been accepted by the public, and they represented a proud era in the history of public health in the United States worthy of emulation in other fields.

I mention the tuberculosis/mental illness parallel because it is instructive to see how, even in the Public Health Service, the tuberculosis model appeared ideal for the control of a chronic, serious illness. Great credibility for public health measures had been garnered by many decades of continuing success. Faith in the power of science has been translated into public policy on many problems, including drugs, alcohol, and tobacco. With regard to alcohol, there has been a gradual movement from perceiving it as a beverage to seeing it as a toxin. Various political and social measures have been taken as a result of that changing perception. Medical discoveries and scientific assertions carry enormous influence, particularly in American society. I call your attention to the fact that there is not a single red apple in this room at this moment. Is this coincidence, or are have we been influenced by recent reports about the toxicity of apples treated with Alar®? And certainly there is no smoking.

As interpreted by public health authorities, medical beliefs may imply the need to take measures that invade privacy or restrict personal freedom, measures that normally would require prolonged political debate or not be countenanced at all. Because public health authorities make such recommendations to achieve health and defeat illness, few question their motives. Their goal is the health of all, but the scope of their proposals can be impressive. For example, Dr. Herman Biggs, writing in 1904 on the administrative control of tuberculosis, said that in the case of a consumptive mother, a single parent with several small children, if "instructions are not followed and proper precautions are not taken, then the family should be broken up. The mother should be removed to an institution, if necessary by force, and the children otherwise provided for." In a more comprehensive mood, Dr. Biggs also wrote: "Homeless, friendless, dependent, dissipated and vicious consumptives are likely to be most dangerous to the community. If not cared for in an institution, they are wandering from place to place, living in lodging houses or sleeping in hallways or wherever cover can be found; negligent as to the disposal of their expectoration and disseminating infection in every place they visit. Such cases must be provided for by the sanitary authorities at any cost, and, if necessary they must be removed by force to proper institutions and there detained." What conclusions did Dr. Biggs draw from his chart? He said: "I do believe that the very great and rapid fall in the tuberculous death rate is the direct result of the application of these measures." He would "regard the experience of New York City as furnishing conclusive proof" of the wisdom of his suggestions.[2]

The public health measures that the AIDS issue has stimulated concerning connections between measures taken and decline in mortality thus require careful reconsideration by historians. We must look at them critically and fairly. In New Haven, we are working our way through the Klebs Tuberculosis Collection. It is an interesting collection, containing 4,000 books, many thousands of reprints, and other materials collected over a lifetime by Edwin Klebs, the *Klebsiella* discoverer, and his son Arnold. They have been covered with dust for 40 years in the basement of the Yale Medical Library. This is the first time anyone has gone through some of this information. That is what I meant when I said a light is being thrown on old documents because of concern with AIDS.

In this process, multiple attitudes toward tuberculosis control have been revealed. Among the most interesting, and in contrast to that of Biggs, is that of Arnold Klebs, himself an authority on tuberculosis. In response to the question, "Should every case of tuberculosis be reported?", Klebs stated in 1918 that it was unnecessary, because it would have no theoretical value. He said: "At our present state of knowledge only cases could be reported which are either infected or suspected to be infected, and since the mere fact of infection is of slight practical importance, the measure of reporting would provoke merely an intrusion into private affairs without any adequate compensation to the collectivity."[3]

To the key question of what should be done with the "incorrigible tuberculous," who was more often called "the careless consumptive," he replied, "I presume by 'incorrigible' is meant the indiscriminant spitter, the drunkard, the filthy, et cetera. They belong to the large class of the socially irresponsible and have to be dealt with by disciplinary methods, but not because they are tuberculous. A state without order is unthinkable, but the enforcement of order must be based on broad, hygienic ethical and legal principles, not on isolated scientific theories which are constantly subject to change with increasing knowledge."[4]

That constitutes a very different point of view from that of Herman Biggs. The history of tuberculosis has been repeatedly studied, but I would suggest that contemporary debate over public health methods presents us with an opportunity, in fact a duty, to re-examine two questions: (1) the effectiveness of traditional public health measures in the decline of tuberculosis mortality; and (2) the political role assumed by public health authorities.

Notes

1. F. B. Smith. *The Retreat of Tuberculosis, 1850-1950.* London: Croom Helm, 1988, p. 236.

2. Herman M. Biggs. "The Administrative Control of Tuberculosis." *The Medical News* 84 (1904): 337–45; quotations from pp. 341, 345.

3. Arnold C. Klebs. "The Tuberculosis Problem: One Point of View." *American Review of Tuberculosis* 2 (1918): 106–108.

4. *Ibid.*

Discussion

Participant: I found what you said enormously interesting because I support a kind of social hygiene movement, and Biggs is central to that. I don't want to put words in your mouth, but it seems to me you are implying that we need critical studies focused on policy formation, on social groups, and on the dynamic interrelationships among groups to explain why we persist in applying this tuberculosis model to sexually transmitted diseases. Am I correct?

Speaker: Yes. By "critical," of course, I mean fair evaluations. I think that public health campaigns are imbued with such righteous feeling—after all, you are helping people—that opposition may seem irrational. And I think that although public health and public health measures are hallowed in the 20th century, they must be re-evaluated and be seen as part of the social dynamics of the time, and not necessarily as pure truth. They may or may not have been efficient responses to illness. Public health has done many wonderful things, but the confidence of the authorities in their prescription for the populace has not always matched the achievements of their recommendations. I'm saying this is an important opportunity for medical historians to re-examine policies that have been considered too sacred even to question.

Participant: Could you speculate about why volunteer societies, such as the National Tuberculosis Association, arose, and why the claim that public health methods worked came only after the disease was in significant decline?

Speaker: It is a very interesting question as to whether volunteer societies arise to claim success as the crisis is ebbing and then see their policies as having caused the decline. The tuberculosis movement, of course, raised issues that affected practically every home in America. In addition, after discovery of the tubercle bacillus, specific recommendations for behaviorial change followed. There was a scientific rationale for what Dr. Biggs recommended. To have a terrible problem and to have weapons with which to fight it strongly facilitated a broad-based popular movement.

Participant: I think what you are suggesting is worthy of pursuit. On the other hand, I'm not persuaded that it is possible to get to the truth because if a group does not report, then we have no data. How, then, would one study the impact of not reporting tuberculosis, for example, to the public health authorities?

Speaker: During the heyday of the study of tuberculosis, there were a great many studies comparing cities, states, or registration localities, places where certain techniques were used. Dr. Biggs claimed that his Draconian measures resulted in a faster decline of tuberculosis in New York City than in those cities where his method was not used. It is a difficult study, but there are data out there.

Participant: Is uncertainty eternal? Is there any point at which there is a higher probability of knowledge that permits proper public health policy?

Speaker: I think that you could have greater certainty than we had with tuberculosis. For example, with regard to inoculation against smallpox, I am quite persuaded. I think that there are different levels of certainty. In the anti-tuberculosis campaigns, certain policies that were taken as settled and applied to the public are worthy of reexamination.

Participant: In which camp would you put the antismoking campaign?

Speaker: It is easier for me to deal with the alcohol question because I've never smoked and I can't think of positive things about smoking. I have at times drunk alcohol, and I can understand both points of view on it. It is easy to follow through American history how attitudes shift from seeing it as a beverage to viewing it as a toxin. I think one of the great questions is where to put fetal alcohol syndrome. Some investigators think it is an overblown problem. Other researchers feel that it is urgent to take powerful steps to stop drinking during pregnancy.

New York City Epidemics and History for the Public

Bert Hansen, Ph.D.

The exhibit I am preparing is called "Epidemic: Public Health Crises in New York."* It will illustrate the experiences of epidemic diseases in the New York City area, from the earliest European settlements to the present. Plans are for it to open in November 1991 at the Museum of the City of New York. As an academic, I find it wonderful to have this long a timeframe to plan something. On the other hand, an exhibition on epidemics ties closely into people's experiences of the present epidemic, and it is a little frightening to be in the dark about what will be occupying people's minds nearly 3 years from now. Will people be desperate for history as a relief from the growing chaos? Or will they be angry with us for wasting time and money on something they deem irrelevant? It is hard to know. It is also hard to know the primary concerns that people will bring to such an exhibit; they could be quite different from their concerns today.

The scope of the exhibit is relatively restricted. It will not try to inform visitors about all public health activities or even about all epidemics in the city's history. Unlike an article or book, which can be read at leisure and reread when interest prompts, this kind of walk-through exhibit has the limitations of a single exposure, further constrained by visitors' time and attention span. You get only one chance with most people; it is not something to which they can easily return hours or weeks later. A book of historians' essays, however, will be published

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*Since presenting this paper, Dr. Hansen has resigned as guest curator for this exhibit. Mr. Kenneth Yellis has been named to succeed him.

to accompany the exhibit, and this we hope will offer more sustained access to the subject.

My thinking is shaped by a picture of the visitors' understandings and misunderstandings about disease and public health, and about history in general. My current image of a general public audience is based in part on students—clearly not the best sample, but readily available since they share their ideas and experiences with me in the classroom. And they do represent to some extent the thinking of their parents, their high school teachers, and others. My other informal sampling comes from network television employees. Because of AIDS, historians of medicine are now in demand. We are asked lots of questions. We are put on radio and TV. Some of my more informative conversations have been not with the producers and the interviewers, but with the technicians—the camera and sound people. After the interview, when we're off the air, they bring up questions and concerns about AIDS and more general questions about disease in history. These conversations have revealed a great deal to me about people's curiosity about history and about the depths and the pervasiveness of misunderstandings.

What can history contribute to public understanding of the AIDS crisis? What are my aspirations for its utility in the present situation? First, I want to challenge what I like to call "Hollywood history." I think the way Hollywood films have presented history to us implies that people in the past were "really just like us." Perhaps they wear wigs, travel in wooden boats or stagecoaches, or wear Roman togas. But their complexions are as clean and as well scrubbed, and their teeth are as brushed and as well preserved, as most of ours. But more important, their psychology is our psychology. This is a great distortion, and I would hope to be able to use this exhibit to show how different people were in the past, to undercut the kind of psychology that implies "There is one human nature, and it doesn't matter what their hairstyle is or their clothing, or their government or material conditions, or their diseases—inside they're really just like us."

On the other hand, I don't want to take that too far. I don't want to go so far as to make people in the past seem alien. My students, for example, are appalled that mid-19th-century New Yorkers were comfortable with pigs running through the streets. They find it funny, but they also find it hard to imagine. They are appalled at the fact that 19th-century doctors saw no reason to wash their hands between patients, or to wash their hands before a meal rather than after it. When I speak about a privy overflowing in a tenement backyard and the number of people who use that privy and the lack of running water, my students are simply disgusted. They can't imagine that these people are anything like them. A connection must be made between us and our ancestors.

When you look back at early ideas in the history of science and medicine, it is easy to award "gold stars" to some and bad marks to others. It is easy, in retrospect, to claim that someone had the "right" idea. I want to challenge this kind of ahistorical evaluation, and as much as possible the exhibit will be designed to minimize distortion of the past.

A closely related goal is to emphasize that the only basis for understanding and for evaluating people and their actions is context. For example, the rules about isolating individuals suffering from epidemic disease, mentioned earlier, should be judged good or bad, reasonable or not, in terms of the contemporary—not the modern—understanding of the disease, the nature of the contemporary social realities and possibilities. History in the AIDS epidemic must offer more than a source of nice examples and handy quotations; it should offer practice in appreciating context's visible and not-so-visible features.

I also hope that an exhibit on epidemics in history will weaken hysteria and diminish the attractiveness of false solutions. I am convinced that there have been major problems in the AIDS crisis so far, and I think that authorities have done too little to oppose easy and false solutions.

I hope to empower the individuals who come to view the exhibit. Thousands will come to the museum for this show. Numerous school groups will certainly come through. I would like people to gain a stronger, clearer understanding of their own possibilities in the midst of a social crisis, in this health crisis. My rule of thumb on this (to borrow from a 19th-century historian) is that people make their own history, but they do not choose the circumstances they make it in. I urge my history students always to keep in mind that individuals do have a role—they do make decisions, they do "make history"—but only within the context of larger forces and situations. If we write history as if it were only impersonal forces, we have failed. On the other hand, I do not want to imply that all historical events result from personal choices, or that simply by force of will people can control their destiny.

I also want to restore an awareness of, a respect for, and even an enthusiasm for public health and epidemiology. As I look at the last few decades, I think that public health has become largely invisible in Americans' understanding of their world. Part of the problem is that people generally seem to be more readily excitable about therapies than about prevention. Public health's structures, means, and effects all seem greatly underappreciated. The long-standing tendency to be more concerned with cure than prevention has been amplified in the last few decades by spectacular new surgical therapies, antibiotics, and other clinical developments that shadow issues such as sanitation, vaccination, and accumulation of morbidity statistics. And the decrease in funding for public health relative to clinical medicine lessens its visibility and the public's sense of its value.

I believe the exhibit will work best if people find in it some familiar and expected things, rather than only the unfamiliar, the antique, the quaint, and the exotic. Of course, we will need to limit the number of diseases and epidemics, but the full chronology will be included. I chose to bring tuberculosis into the exhibit, even though it is not epidemic in the way that smallpox and cholera were, because I think it is very revealing of people's response to epidemic disease.

The exhibit will be arranged chronologically in six sections. The last section, on AIDS, seems to me the best place to make more explicit some of the "lessons" prompted by the preceding sections, both to pull things together and to give people a positive framework for confronting what will inevitably be powerful and painful images and artifacts of the present.

I hope that people will carry away a sense that the past can be useful in understanding the present, and in responding effectively—but only when past and present contexts are taken fully into account. One must understand, for example, that many ideas and techniques from the past are inappropriate today, no matter how hallowed by tradition. I hope people will see that panic, though common, is not inevitable. I hope people will appreciate how epidemics reveal the ways in which religious, class, and political differences deeply affect feelings, policies, and actions in public health. My intention will not be to devalue these factors, but rather to help us notice them, to take them into account in cultivating more intelligent and humane responses. I hope people will carry away the lesson that public leadership, both governmental and individual, is essential for effective and humane response. I also hope that they will garner some awareness of how New York City's history was typical of wider experience, and how it was unique.

It will be possible for visitors to examine various aspects of the responses to AIDS—lay and professional, governmental and personal, hideous and glorious, selfish and selfless, by the well and by the sick, by organized philanthropy and by nameless individuals like themselves. It will be necessary to convey the sense that new contexts may be quite different from those of the past. In the 19th century, for example, when the modes of transmission had not been established, it was not considered irrational to express one's fear of cholera contagion from a hospital in one's neighborhood by setting it on fire, however anarchic or uncharitable it might have been. Today, however, refusing to have a nursing home for AIDS patients on one's block for fear of transmission is considered thoroughly irrational, and it is a response that must be vigorously opposed, however strong its historical precedents.

Health policy is something that must be to be shared with those who visit our exhibit—both the ways of thinking and the policies themselves. Yet I find it hard to imagine what kind of artifacts and images I can use to make the abstract generalizations of policy something concrete and vital. If any of you have suggestions of how to make health policy visible and tangible, I welcome your ideas.

Discussion

Participant: It seems to me you're running a great risk having an AIDS section as one of six. Are you going to be objective, giving various sides their points of view, or will you have a point of view? I think that you will have to be prepared for political reaction when this section of the exhibit is reviewed.

Speaker: It seems to me that to do an exhibit on epidemics in New York's history and stop before AIDS is to frustrate the people that you want to reach. I think there has to be something there, both in the book and in the exhibit. What will be there? How much? These are the hard questions. Yes, it has to have a point of view. There is no writing or teaching that doesn't have some point of view. But the information, issues, and presentation have yet to be worked out. If I had to prepare the exhibit tomorrow it would consist mostly of charts and graphs that show quantitatively what has happened over the decade of the epidemic, showing cases by area, growth, funding, numbers of organizations involved, philanthropic dollars, government dollars, and so on. Then there would be photographs and artifacts.

There is the delicate and difficult problem of preventing the AIDS section from overwhelming the exhibit as a whole. I hope to integrate it by recapping images and quotations from other parts of the exhibit, to echo themes and lessons that were raised earlier. This may not be the best way to do it; it may not be feasible or visually interesting; we are concerned about this.

Participant: You haven't touched on the theme of the personal impact of epidemics on families. It seems to me that one of the enduring themes in the history of epidemics is the social disorganization and the disruptions of families which are caused by the deaths of many family members at once. In the case of AIDS, families of homosexual patients or drug-addicted patients may already be polarized and in crisis or conflict, and the illness emerges in that setting. Placing a patient in intensive care can raise barriers; health care practitioners may discourage family members from visiting the patient in those situations. I was curious whether you saw that as a possible theme for the exhibit. It seems to me it would be a theme with which the public would have a personal connection, one to consider in addition to the broader policy issues you discussed.

Speaker: I appreciate your comments.

Participant: All three papers were exciting, and if you put them together it seems you have a marvelous opportunity to look at ethnic history and its response to public health measures in New York City. There are films from the ethnic groups of the Lower East Side, some of which could be used to show how different groups respond to people with AIDS. If you go back to the work of Jacob Riis and others, you might be able to examine not only public health but the response to public health and the importance of ethnic history in shaping New York in particular.

Speaker: Absolutely. It certainly is one of the themes of the exhibit and of the book of essays that goes with it. Alan Kraut has agreed to be the author of the book's chapter on immigrants, and other chapters will include ethnic factors as well. A student of mine recently did a very interesting paper on newspaper coverage of the polio epidemic in 1916, exploring the differences between the mainstream newspapers and the German and Italian immigrant papers. The paper showed the differences in attitudes and understandings. There is a fertile field there. Again, the frustration is that one could almost do a full exhibit just on ethnicity and epidemics in New York's history. We are constantly shaving things off because there are so many striking things to include. But ethnicity is certainly a theme that will be developed throughout the exhibit.

Participant: John Burnham wrote an interesting book on the phenomenon of health education and its decline. His work makes clear the importance of reconsidering health education. Health education is important in the AIDS campaign. Nevertheless, I find myself in the same quandary that Robert Merton was in when he had to defend middle-range theory against its inadequate explanatory powers. To paraphrase his response: How can you expect me to push the bus that I am riding on?

I think we find ourselves in a similar situation when we educate the public while we are trying to determine policy. It is a difficult feat to accomplish.

I agree with your interest in education. What you're doing is infinitely superior to the medical jeremiads of the earlier part of the century, such as Prince Morrow's traveling exhibit, a "chamber of horrors" that became the model for early military sex education films.

The importance of health education to past medical movements is clear. Health education was an integral part of the antituberculosis movement and the antisyphilis campaign.

In the contemporary situation, it is critically important that we not fragment education from policy as we communicate with the larger public. I hope we do not start with presentist assumptions about public health and, as historians, try to be critical at the same time.

Commentary

Caroline Hannaway, Ph.D.

My task as commentator is not to give another formal presentation, but instead to raise questions for the important discussion groups that follow. If some of my questions seem large in scope, they are meant to stimulate the discussion that this workshop hopes to generate.

Dr. Risse's overview of the history of epidemiology has given us a general account of the work that has been done in the field. What struck me, however, about this presentation was how much we still do not know about disease in the past. Now, that is obviously a truism, but there are undoubtedly large areas of history of disease that have not received scholarly attention, and plenty of material for historians to work on.

One area that needs further investigation is the history of disease theory. Erwin Ackerknecht wrote about the concepts of miasmata and contagion back in the late 1940's, but discussion of issues such as these has not advanced much since. Valuable work has been accomplished on the social context in which diseases occurred, and examination of the social construction of disease is very popular, but we still have not systematically defined what most of the people concerned with questions of disease (public health officials, physicians, and ordinary citizens) thought about the nature, course, and transmission of disease. We have only unsubtle ideas about the relationship of sin to disease changing to "scientific" models about the causes of disease. I think a better appreciation of theories of disease would enhance our study of the history of disease.

I would also argue that we need better definition of epidemics over time. At present, the terminology is confused. There is the descriptive phrase "epidemic events." "Plague" is frequently used as synonymous with "epidemic." But we do not seem to consider epidemics as a continuing phenomenon. Then, too, the word "endemic" has not yet been mentioned at all. The word "chronic" is, I think, used sometimes to mean "endemic." These are not just semantic quibbles; they pertain to our interpretation of AIDS. There is the possibility, for instance, that AIDS is an endemic disease, or is on the way to becoming one. It may not be just an epidemic event that will one day go away. Perhaps its pattern will be different from that of cholera. The descriptive terminology of disease events needs, I think, more discussion.

We also have to consider the general question of how much the study of past epidemic events helps in considering AIDS. Has society changed in ways that are going to make such a discussion irrelevant? We historians do not want to think that this is the case, but we should consider the question.

In comparing AIDS with other diseases, we have not paid sufficient attention to the influenza model. Perhaps the major epidemic event of the early 20th century was the influenza outbreak in 1918-19 that killed millions of people around the world. The disease was swift-moving, appeared suddenly, and provoked a tremendous crisis in societies everywhere. More people died from this influenza epidemic than died in World War I from all causes. I would like to see the influenza model brought into discussion of historical models for AIDS and compared with cholera models, tuberculosis models, venereal disease models, and others.

Work in another area of the history of medicine may offer guidance in the historical analysis of AIDS. Some of the most exciting new work in the history of disease is investigating the effects of the transfer of disease from one culture to another. Two recent collections of essays assess what is often now described as "colonial medicine" or "imperial medicine" and investigate European responses in colonial territories to the diseases encountered in India, Africa, the Caribbean, the Pacific, and the Americas. This is work of which historians of AIDS need be aware. AIDS is also a disease that has crossed and is crossing from one culture to another, and the complex factors impinging on the transfer of the disease and the reaction to it can be illuminated by examination of previous cross-cultural transfers.

Dr. Musto's paper raises a series of issues for consideration, but the major question brought to the fore is that of epidemiological practice versus public health practice. We all know that it piques the medical profession that their endeavors have not been seen by recent historians as being the cause of the decline of disease in the 19th century, especially of tuberculosis. Better nutrition and the facilitation of hygienic measures are receiving the credit.

There is a division in medicine between those in public health and those in medical research or in the pursuit of scientific medicine. Conflicts arise between those who want to spend money on research to understand the characteristics of a disease and find therapies, and those who want to focus on education of the public and maintenance of its health. I do not want to imply that these two visions of the role of medicine are entirely opposed, but certainly the two groups have different agendas. This issue needs to be appreciated in exploring the history of disease.

Dr. Musto's paper also raises the issue of individual rights versus the health of all. This is an age-old dilemma, and in American society where individual rights are strongly advocated and the benefit of the society as a whole often receives less support, it is an issue that has to be considered in careful detail.

Bert Hansen's exhibit sounds fascinating and well worth seeing. He is well aware of the questions that putting up such an exhibit raises. I certainly hope that trial runs of the material are made on schoolchildren, if the purpose of the exhibit is to reach such groups, because he may have to organize the pictures and artifacts somewhat differently. A better definition of what the "general public" is, and which groups within the general public the exhibit aims to reach, would be helpful.

As historians, we know past epidemics suggest that hysteria has always been part of the reaction to epidemics. Are we going to deny history and say that, if we are better informed, hysteria and panic and fearful reactions to disease are going to go away? I do not believe this, and I think it would be untrue to historical evidence to make such a claim. What, then, do we hope to achieve by educational historical exhibits, and what are their functions in the reaction to AIDS?

Workshop 1
Summary of Small Group Discussions

AIDS is a global disease. Although it is tempting to focus on AIDS in the United States, it is incumbent upon historians who write about AIDS to expand their scope and put the disease in its global context. Histories of AIDS in specific geographic locales will be essential, as will comparative studies, such as international travel restrictions formerly placed on people with AIDS compared with the 19th-century certificate campaigns for cholera and smallpox.

Historians must examine their purposes in writing about AIDS and must define their intended audiences. Is their goal primarily to bring the topic of AIDS into the orbit of professional discourse? Or is theirs a grander, more political agenda? Do they hope to enhance public education or their own images? Should AIDS historians distance themselves from current events so as to be purely objective, or be responsive to current events so as to present a comprehensive view? The answers to these questions will help determine how the history of AIDS is written and how today's historical writings may be viewed by future readers with different perspectives.

Historians should be careful of methodological pitfalls. Although comparisons and contrasts are important, historians must be aware of which factors are suitable for comparisons between diseases at different times and in different places. For example, we must carefully consider which criteria are relevant in attempting to compare syphilis in the Renaissance with cholera in the 19th century or with AIDS in the 20th century. The definition of terms—such as epidemic and chronic disease—also needs more attention. Historians should be careful in their judgments about the response of particular societies to particular disease events. They must be aware of limitations imposed by factors such as social organization and should examine their interpretations carefully for presentist bias.

Historians should set AIDS within the context of other sexually transmitted diseases. Additional research on the history of sexually transmitted diseases is needed in order to accomplish this. Two issues, in particular, were recommended for further study:

- Historians could fruitfully examine the boundaries of tolerance: How much do they change over time? What are now called alternative lifestyles have antecedents in some of the utopian communities of the 19th century. When the tenets of these communities clashed with antivice campaigns, were community responses similar or different over time? How did the institutionalization of and tolerance toward alternative lifestyles that emerged in the 1960's and 1970's affect the response to AIDS?
- The role of the medical profession in sexually transmitted diseases also needs examination. How did physicians respond to individual patients and to disease events? What effect, if any, did particular disease outbreaks have on medical education?

Historians need a greater awareness of the role of public education. They should be familiar with the influence of theories of health education and promotion in their reconstruction of past disease events. The effectiveness of health education campaigns and their relationship to combatting disease should be examined. Historians should assess who the target audience was, who determined that a campaign was necessary, and whether a policy **not** to educate might be the best course with regard to certain health issues. Educational posters and other visual media provide essential data for this analysis. An important tangential issue is that of the allocation of resources to health campaigns. How are resources allocated in defense of the public health? Who decides which disease is worthy of the greatest resources?

Historians must not neglect the social aspects of AIDS. Although historians generally agree that both the biomedical viewpoint and the social viewpoint must be examined and documented, there is concern that the social viewpoint is being neglected. In addition, the history of AIDS should be enriched by including more data from the humanities, such as the work of artists and poets. Specific suggestions for research in this area included the following:

- Historians need to analyze the ways that different racial, ethnic, and social groups have experienced AIDS, and other diseases as well. Religious groups, political groups, and regulatory groups also have certain documentable responses to AIDS which should not be overlooked. We must also keep in mind how each group conceptualized doctors, scientific evidence, and other technical aspects of disease. Finally, we must be aware that even those engaged in the health professions perceive illness and sick people in a variety of ways.
- The AIDS epidemic offers an opportunity to document the viewpoints of health care providers other than physicians. Composed of nurses, orderlies, other health care personnel, and family and friends of sick people, this group often has been ignored in historical studies, even those that focus on recording what patients think and feel. Oral histories provide one mechanism for capturing their viewpoints.
- The nature of health hysteria needs further inquiry. How do the perceptions of victims arise? How does society respond to them?

Historians should examine their rationale for urging greater documentation of AIDS. Is concern about documenting the progress of disease a new phenomenon? Were people involved with cholera in the 19th century concerned with documenting this disease for the future? What forms of documentation have proved most helpful, and what do we wish had also been preserved? Should we try to anticipate the questions that future scholars will want to ask and to formulate collection strategies on the basis of speculation? Addressing these questions may help to provide a philosophical basis for rational collecting strategies.

Workshop 2
Clinical and Biomedical Research Responses to AIDS

Introduction

Victoria A. Harden is the Co-Chair of the AIDS History Group of the American Association for the History of Medicine, historian of the National Institutes of Health, curator of the DeWitt Stetten, Jr. Museum of Medical Research, and host of this conference.

Theodore Hammett is Project Director of the Centers for Disease Control AIDS history project, and Michael Gross is his colleague at Abt Associates, Inc., in Boston, MA.

Alan N. Schechter, a molecular geneticist doing some work on AIDS, is Chief of the Laboratory of Chemical Biology in the National Institute of Diabetes and Digestive and Kidney Diseases.

Bernardino Fantini is a geneticist at the Università di Roma "La Sapienza" in Italy; he is also working on AIDS.

The commentator is Jack Pressman, an Assistant Professor in the Department of the History of Health Sciences at the University of California, San Francisco.

The Biomedical Response to AIDS In Historical Perspective

Victoria A. Harden, Ph.D.

Since emergence of the germ theory in the late 19th century, disease has been increasingly conceptualized in scientific terminology, particularly by members of the biomedical research community, who, unlike historians, journalists, and writers in other interpretative disciplines, rarely speculate in their publications about the larger meaning of disease to society. Thus, the first scientific publication about AIDS, published in the Centers for Disease Control (CDC) *Morbidity and Mortality Weekly Report* in June 1981, spoke of unusual occurrences of *Pneumoncystis carinii* pneumonia in immunosuppressed patients.[1] This article's factual observation that the victims were homosexual, coupled with subsequent reports linking Kaposi's sarcoma and other manifestations of the disease to this population, fueled the social reaction that has been so widely discussed. Within the research community, however, efforts to understand and combat the disease were informed primarily by knowledge about the human immune system, about the agents that attacked it, and about techniques that might permit intervention in the pathological process.

Thus far, the historical community has emphasized the social and political aspects of the AIDS epidemic and has paid scant attention to the scientific ideas and techniques employed against the disease. One notable exception to this is evident in Gerald M. Oppenheimer's paper on the epidemiological construction of AIDS, published recently in the book edited by Elizabeth Fee and Dan Fox, *AIDS: The Burdens of History*.[2] Even in this paper, however, topics are raised that need to be explored further. In his discussion of how a viral etiology for AIDS came to be accepted, for example, Oppenheimer mentions Koch's postulates: those conditions initially promulgated by Robert Koch as being necessary and sufficient to prove *bacterial* etiology of a disease. It is clear that Koch's second postulate has changed to accommodate the study of viruses, and it is to the "current formulation" that Oppenheimer speaks. But other historians might also explain when this change occurred and in what context. Given the current challenge raised by Peter Duesberg to the human immunodeficiency virus (HIV) as the etiological agent of AIDS—a challenge based in part on scientists' ability to satisfy Koch's postulates—such a study would enhance public understanding about the scientific arguments.

In a recent interview with Anthony S. Fauci, NIH Associate Director for AIDS Research, I asked him to speculate on how the biomedical research community would have responded if AIDS had struck in 1955. He said:

> I think it would have been much more frightening than it is now, and it is frightening now. I think we would not have had a clue as to how to combat this disease from a basic scientific standpoint. I think we would have realized just on epidemiological grounds that it was an infectious agent of some sort that was sexually transmitted and transmitted by blood. But about pathogenic mechanisms, we wouldn't have had a clue. We wouldn't have known how even to go about thinking about the virus, much less clone it and develop drugs against it. So within the framework of the catastrophe of AIDS, we're lucky, in the sense that it came at a time when retrovirology, molecular biology, molecular immunology, and immune system studies were at the stage where we could very quickly identify the agent, how it works, the pathogenic mechanisms, its effect on the immune system, etc. If it had happened in 1955, we would have been in very serious trouble.

For historians, Dr. Fauci's key comment was that AIDS came at a time when several fields of scientific inquiry were enormously fruitful. Immediately, questions spring to mind. Why at that time? What produced this sudden flowering of knowledge? When one seeks historical studies of these fields, however, there are few to be found.

What I propose, therefore, is an expansion of what have been called internalist histories of science and medicine with the goal of increasing our understanding of how the biomedical research community has responded to AIDS. Scientists, to be sure, have written review papers or retrospectives about their work, but their literature is often filled with arcane language inaccessible to lay people. It would be helpful if more investigators with scientific expertise could also address the contextual questions that illuminate the history of science for a broader audience. Conversely, historians have a responsibility to tackle the science, and occasionally the mathematics, necessary to write such studies. Having recently completed my work on Rocky Mountain spotted fever, a subject that required understanding of microbiology, immunology, and some molecular biology, I would urge historians to take heart. Not only was it possible to master enough science to write about it—especially because scientists proved to be patient teachers—but it also became an absorbing and rewarding venture into intellectual history.

A number of general areas in scientific history sorely need to be elucidated if we are to understand the response of biomedical investigators to AIDS. The recent history of virology is one broad field needing exploration. Why were human retroviruses not identified until the 1970's? Was it lack of technique, lack of theoretical constructs, or lack of a reason to look for them? Why were retroviruses discovered by cancer researchers instead of infectious disease investigators? Another field in which sources are notably scarce is the post-World War II history of immunology. Debra Jan Bibel has recently published *Milestones in Immunology*, subtitled *An Historical Exploration*.[3] She presents selected papers in immunology from the late 19th century to the present, with comments on the authors and the work. Another book scheduled for publication this year is Arthur M. Silverstein's *A History of Immunology*.[4] The appearance of these works underscores the importance of the field, and both should provide points of departure from which other studies could be done.

Another area of potentially fruitful work relates to biomedical instrumentation. Much immunological progress, for example, would have been impossible without the development of cell sorters. The enzyme-linked immunosorbant assay (ELISA) test, which is the initial test employed to detect HIV infection, is a recently developed technique that has been important in the response to AIDS. Other important techniques that rely on new instrumentation include tissue culture, monoclonal antibodies, and recombinant DNA. The list is long and, to a great extent, has not been addressed by historians.

For those scholars who would undertake the scientific history of AIDS itself, there are many published sources. Both *Science* magazine and the *Journal of the American Medical Association* have published collections of papers on AIDS. These include editorial comments, news summaries, and letters to the editor, in addition to scientific articles.[5] The Federal Government has also published papers on AIDS, collected from the *Morbidity and Mortality Weekly Reports*.[6] The National Library of Medicine (NLM) has recently added a data base, called AIDSLINE®, that extracts citations to literature on AIDS from other data bases. NLM also offers printed bibliographies on AIDS that go back to the earliest papers. One small collection that our office recently transferred to NLM should prove useful to scholars tracing the evolution of thinking on AIDS during the first few years. Sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), it was called the *AIDS Memorandum*, and it circulated among investigators across the country in 1983 and 1984 before papers on AIDS were being published by major journals.

Techniques I am using in my own research to document the response of the National Institutes of Health (NIH) to AIDS include oral histories with many NIH staff members. I hope to talk with investigators, administrators, nurses, technical staff, and perhaps patients. Once transcribed and edited, they will be available to other scholars through NLM and/or the National Archives. I am also working with many NIH offices to help ensure that key documents be preserved for the use of future scholars. Although this project has really just begun, I am encouraged by the positive response from NIH laboratories and offices. People seem to recognize that AIDS represents not only a medical crisis with which the agency must deal, but also a test of how people today respond to a critical human problem. Almost to a person they have been supportive of my requests for help.

The broad body of work that needs to be accomplished to provide a historical perspective on the biomedical response to AIDS will not be accomplished quickly. It is essential, however, if we are to understand this epidemic in all its manifestations. As papers and books are produced, moreover, they may shed considerable light on public understanding of this disease in its social, political, economic, and ecological dimensions.

Notes

1. "*Pneumocystis* pneumonia—Los Angeles." *Morbidity and Mortality Weekly Report* 30 (June 5, 1981): 250–52.

2. Gerald M. Oppenheimer. "In the Eye of the Storm: The Epidemiological Construction of AIDS." *In* Elizabeth Fee and Daniel M. Fox, eds., *AIDS: The Burdens of History.* Berkeley: University of California Press, 1988, pp. 267–300.

3. Debra Jan Bibel, ed. *Milestones in Immunology: A Historical Exploration.* Madison, WI: Science Tech Publishers, 1988.

4. Arthur M. Silverstein. *A History of Immunology.* San Diego: Academic Press, 1989.

5. Ruth Kulstad, ed. *AIDS: Papers from Science, 1982-1985.* Washington, DC: American Association for the Advancement of Science, 1986; Helene M. Cole and George D. Lundberg, eds. *AIDS from the Beginning.* Chicago: American Medical Association, 1986.

6. Centers for Disease Control. *Reports on AIDS Published in the Morbidity and Mortality Weekly Report, June 1981–May 1986.* Atlanta, GA: Department of Health and Human Services, Public Health Service, Centers for Disease Control, n.d., with updates, 1987, 1988.

Discussion

Participant: Will your research examine the competition between the National Cancer Institute and the Pasteur Institute, and, if so, will it be the definitive history?

Speaker: We will certainly examine the process through which the etiology of AIDS was determined. The story will be as accurate as we can make it, but our historical colleagues will judge which, if any, account stands as "the definitive" history.

Historical Factors in Federal AIDS Prevention Efforts Sponsored by the U.S. Centers for Disease Control

Theodore Hammett, Ph.D., and
Michael Gross, Ph.D.

Abt Associates is a multidisciplinary social policy research firm in Cambridge, MA. Abt Associates was awarded a contract by the Centers for Disease Control (CDC) to conduct a historical study of CDC's efforts to prevent and control AIDS. The result of this project is to be a scholarly monograph suitable for publication. Another aspect of the project is to develop recommendations for better preservation of the documentary record of CDC's response to AIDS in the future.

Two questions naturally arise concerning our project. First, what were CDC's motivations in funding such a project? Second, how are we as historians affected by having, in effect, been hired by the subjects of our work? As to the motivations of CDC, we think that CDC is proud of its record on AIDS and wanted to see its accomplishments documented to assist the public health community in understanding the Federal role in responding to an epidemic of this nature. From what we have seen and heard so far, we believe that the agency has reason to be proud of its accomplishments in addressing the epidemic under very difficult circumstances.

As to the effect of our being hired by the subjects of our research, CDC has given us access to all documentation we have requested and all individuals we wished to interview. There has been no pressure—either explicit or implicit—to present a congratulatory message. CDC's only interest has been in developing an objective, properly documented historical account.

CDC's AIDS prevention activities were divided into four basic categories. The first category was publication in the *Morbidity and Mortality Weekly Report* (*MMWR*) of prevention guidelines, directed to practices and groups of individuals who might be affected by the epidemic. Publication of *MMWR* guidelines began in 1982. The second category was development of initiatives to address the problem of transmission of HIV through blood. These interventions, which antedated antibody testing and primarily involved donor deferral programs, began in 1983. The third category, broad prevention programs involving issuance of grants and cooperative agreements for counseling, testing, surveillance, health education and risk reduction, minority initiatives, and school health education programs, began in 1985. By 1987, these efforts were supplemented by a massive national media campaign, including a public information brochure that was mailed to every household in the United States and Puerto Rico. The fourth category of CDC activity was conferences and meetings on blood transmission issues, minority issues, and other issues.

Two preliminary themes have emerged from our investigation. The first is that, as facts about the virus and its means of transmission became clear in 1981 and 1982, CDC began to issue guidelines for prevention in the *MMWR*. For example, practices that health care workers could take to protect themselves were outlined. CDC also began to institute donor deferral programs to prevent further contamination of the blood supply. Second, when the agent itself was identified in 1983 and 1984, and when the serologic test for antibodies to the virus became available in 1985, a chain reaction occurred. For the first time, large funding increases for AIDS were appropriated, and they, in turn, triggered CDC's involvement in broader prevention programs in the community. These themes run through the chronology and have guided our initial thinking.

What influenced the timing and scope of CDC's prevention efforts? We are examining three broad areas: 1) economic, 2) biomedical and epidemiologic, and 3) political. The first and most important of these was the climate of Reaganomics in which the response to AIDS had to be engineered. The AIDS epidemic hit just when the Reagan Administration was proposing massive cuts in CDC's budget. Throughout the first years of the epidemic, there were persistent funding problems; and even later, there were ceilings on personnel mandated by the Office of Management and Budget (OMB), that limited CDC activities despite an increase in funding.

Second, in the biomedical and epidemiological areas, several key developments helped initiate and further prevention efforts. First, the existence of a transmissible agent was established by epidemiologic investigations conducted by CDC researchers. Their findings established the basic ways in that the agent was transmitted, leading to guidelines that remained essentially unchanged once the etiologic agent was isolated. Following identification of the agent itself, CDC played a major role in developing a serologic test for antibodies to the virus and deploying it in the field to advise persons at high risk of exposure of their infection status.

Political factors also influenced CDC's prevention measures. Throughout the epidemic, CDC has negotiated a science-based program that has had to withstand criticism from a conservative administration which has little sympathy for homosexuals and IV drug users, the groups initially affected by the epidemic. The homosexual community has demanded additional funding, while remaining suspicious of efforts to intervene in ways that might threaten or appear to threaten privacy or confidentiality. In formulating science-based prevention guidelines, a key CDC approach was to convene consensus conferences of scientific experts to review draft documents.

In addressing the epidemic in minority communities, particularly the black community, for the first few years CDC moved cautiously in response to minorities' denial of the extent to which AIDS was a problem. Later, these same communities became angry and resentful at not receiving adequate funding for prevention measures, just when CDC had succeeded in targeting funds specifically for minority prevention programs.

As we proceed with the project, we will refine our skeletal outline for describing CDC's preventive response to AIDS.

Basic Research Related to AIDS

Alan N. Schechter, M.D.

I take as my point of departure a short section from the book by Randy Shilts, *And the Band Played On*, published in 1987 by St. Martin's Press and recently reissued in paperback. This book has become the major chronology of the AIDS epidemic, both in terms of the disease and in terms of the response of officials in government, including scientists and physicians. It is a powerfully written book, and it is clear that the heros of the book are largely the physicians in hospitals in New York and Los Angeles and San Francisco who took care of individual AIDS patients and recognized the disease as a disease between 1980 and 1982. As a scientist, however, I find deeply disturbing one of the other themes in the book. It is well summarized in the preface:

> But from 1980 when the first isolated gay men began falling ill from strange and exotic ailments, nearly five years passed before all of these institutions, medicine, public health, the federal and private scientific research establishments, the mass media, and the gay community's leadership mobilized the way they should in time of threat. The story of these five years of AIDS in America is a drama of national failure played out against the backdrop of needless death.
>
> People died while Reagan administration officials ignored pleas from government scientists and did not allocate adequate funding for AIDS research until the epidemic had already spread throughout the country.
>
> People died while scientists did not at first devote appropriate attention to the epidemic because they perceived little prestige to be gained in studying a homosexual affliction. Even after this denial faded, people died while some scientists, most notably those in the employ of the United States government, competed rather than collaborated in international research efforts and so divided attention and energy away from the central struggle against the disease itself.[1]

I think those paragraphs and the theme they represent are totally wrong, totally unsupportable, and counter to the actual response of the scientific community. I think it is a major disservice to the individuals who suffer from the disease, as well as disrespectful of the scientists who were involved in the disease from the beginning and who, in retrospect, responded in as rapid and organized a fashion as has ever been the case for any activity of this complexity and this difficulty.

Robert Gallo and Luc Montagnier published a chronology of AIDS research after extensive meetings to iron out their differences in understanding who deserved credit for what.[2] On the one hand, their chronology obviously reflects a subtle agreement between them to show each in the best possible light. On the other hand, I think it is clear to anyone who has examined the scientific literature—the primary journals themselves and other chronologies that have been published—that their chronology is as accurate as anything that has been published. I think very few people would disagree with it substantively.

It is important to recognize that the disease was first clearly recognized by physicians in 1980 and defined by the Centers for Disease Control (CDC) in *Morbidity and Mortality Weekly Report* (*MMWR*) and in a paper in the *New England Journal of Medicine* in 1981. In 1982, several other papers followed. In 1981 and 1982, even before the papers appeared, the hematology and infectious disease communities in this country were aware of it. The academic community quickly became concerned about the existence of a new disease.

In 1982, on the basis of the collected data, the CDC suggested that the disease was probably infectious in nature. During the first year or two, however, that was not at all clear. Amazingly, by February 1983, Robert Gallo and collaborators here at NIH felt confident enough to suggest at a conference that one of the viruses they were studying—the human retroviruses, HTLV-I and HTLV-II—might be the etiological agent. There was skepticism about that, and, indeed, the idea turned out to be incorrect. In May 1983, Montagnier published a paper in *Science* that referred to a new retrovirus, which he called LAV, and which he believed was causing AIDS. There was much uncertainty about his claim. I was aware of this in my own discussions with people at the time. By September 1983, Gallo and his colleagues realized that Montagnier was correct, and they followed up the work, publishing several articles in early 1984 in *Science* that confirmed the Montagnier's finding. Hence, within 1 year the scientific community was convinced that this retrovirus caused AIDS, and it mobilized to characterize and understand the virus.

One must understand that in the 10 years before these findings, a whole new field of biomedical research had evolved from nothing—the field of retrovirology. In 1968 and 1970, David Baltimore and Howard Temin independently realized that there was a new enzyme and a new path of genetic information, the enzyme being reverse transcriptase and the new path of genetic information being RNA leading to the synthesis of DNA, rather than the reverse. For this discovery they won a Nobel Prize. That information allowed the characterization in 1970 of a new class of viruses, retroviruses.

Although retroviruses had been recognized in a number of animal systems, they were not previously known in humans. At the time, it was not at all clear; most people remained skeptical that retroviruses existed in humans. In 1976, Gallo and colleagues, in trying to study disease in humans, realized they had to grow human immunological cells (T-cells), and they worked out a method that in retrospect involved the isolation of a factor we now know is T-cell growth factor, or IL-2, which allowed human lymphocytes to be grown in culture. That technical advance led within a couple of years to the demonstration that human retroviruses did indeed exist. Gallo and his colleagues described the HTLV-I and HTLV-II retroviruses, which cause, respectively, adult T-cell leukemia and hairy cell leukemia. Moreover, Montagnier spent a period of time training with Gallo, and it was because of this background work on human retroviruses that both Gallo and Montagnier were able to find the HIV retrovirus within a year and then quickly develop immunological tests and molecular genetic tests.

Molecular immunology also advanced extraordinarily during this 10-year period. Knowledge about immunology had so advanced by the early 1980's that the molecular and cellular immunology of AIDS could be clearly established very quickly once the infectious nature of the disease and its viral etiology were recognized.

What was the response of the scientific community to all of this? To answer this question, I have made use of the

AIDSLINE® data base that the National Library of Medicine (NLM) has recently established. It collates all of the articles on AIDS research that are published in the journals that it indexes. Articles about AIDS grew from a handful in 1981, including those in the CDC's *MMWR*s. There were additional articles in 1982, and once the disease was well characterized and recognized as unique, the number of workers involved increased significantly, as manifest in their publications. Published papers appear months, in some cases even a year, after submission. One must therefore be aware that the work published in 1983 or 1984 was done 6 months to a year and a half earlier. By 1983, 500 papers on AIDS had been published; by 1985, there were close to 2,000. The figure is rising exponentially. If the burst of activity in AIDS research continues at this rate, all published scientific papers will be on AIDS within the next 10 years. Obviously, the curve will have to level off.

There is no doubt that the scientific community was interested and poised to do whatever it could. Many of these papers were phenomenological or clinical descriptions. Some, especially at the beginning, were just plain wrong. I am familiar with a number of papers published in 1982 and 1983 with really bizarre hypotheses that are, fortunately, largely forgotten.

Basic science is my own interest, and I have attempted to identify from this total set those papers that concerned basic research. That eliminates descriptive papers and reviews and focuses on basic work in molecular virology, molecular immunology, and molecular genetics. By searching the data base with subheads, I generated another set of papers aimed primarily at understanding the molecular pathophysiology of the virus.

There were virtually no basic science papers on AIDS until the first papers on viral etiology were published in 1983. By now, the basic science studies constitute about 40 to 50 percent of the total publications. This reflects, I believe, the active involvement of scientists throughout the world, especially in the United States, who have something to contribute to AIDS. There is now almost a surfeit of investigators trying to make contributions in AIDS basic research.

Here at NIH, the Office of the Director set up a special program within our Intramural Research Program to encourage investigators to work on AIDS. It was not aimed at the major laboratories of Fauci and Gallo and Malcolm Martin and others, but at other laboratories that might wish to become involved. Five million dollars of intramural money was set aside for such work. Between 60 and 70 investigators applied for that money. About half of them were funded, and the program is now in its third year. My own research on AIDS, and on the TAK protein specifically, is funded by that internal mechanism. There was a recompetition this year, and a large number of laboratories applied for these funds.

The mechanism is called the NIH Intramural AIDS-Targeted Antiviral Program. Many Institutes are involved: the National Institute of Dental Research (NIDR); the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK); the National Institute of Allergy and Infectious Diseases (NIAID); the National Cancer Institute (NCI); the Division of Computer Research and Technology—this program involves almost every Institute and every division at the NIH. The range of topics includes transgenic mice as a model of HIV pathogenesis; structural studies of viral proteins and their complexes with drugs and ligands by nuclear magnetic resonance spectroscopy; inhibition of the ribonucleoside activity of reverse transcriptase *in vivo*; *in vitro* identification of sequences likely to be immunodominant; and recognition sites for AIDS, immune T-cells, and use of these in vaccine development.

The intramural NIH program, of course, represents only a small component of the total response of the American scientific community to AIDS. Through NIH grants, the pharmaceutical industry, and other granting mechanisms, the scientific community has done an amazing job. On the basis of my observations during the last 8 or 9 years, this has been the most efficient, concentrated, and productive attack ever mounted on a disease. If the disease had occurred before 1955—even had it occurred in 1975 or 1978—we would still be very much in the dark. We might eventually have gotten to this point, but several years later. It was only because of the advent of molecular immunology and molecular virology, especially retrovirology, that were we in a position to understand the etiology and pathogenesis so rapidly.

One can compare the speed and efficiency with which knowledge about AIDS was accumulated to the Manhattan Project during World War II. Whether this work will lead to effective prevention and a cure in the near future is certainly not yet clear. Already, however, we have realized major benefits from this explosion of effort. The level of fear has diminished because the disease was understood so rapidly. The blood supply has become essentially safe now, with risk at about one in many millions. We can now make definitive diagnoses with immunological reagents, and there is reasonable hope that vaccines and pharmacological treatment will be developed. The attacks of Randy Shilts notwithstanding, the scientific community, I believe, performed ably. Although research has not yet cured the disease, I think it is highly unlikely that in other circumstances more could have been done.

Notes

1. Randy Shilts. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: St. Martin's Press, 1987; p. xxii.

2. Robert C. Gallo and Luc Montagnier. "The Chronology of AIDS Research." *Nature* 326 (1987): 435-36.

Discussion

Dr. Harden: Dr. Schechter, Dr. Hammett, Dr. Gross, and I are all either associated with government agencies or writing about them. I think all of us have been impressed with the scientific efforts mounted by our agencies against AIDS, and thus surprised by the sometimes vitriolic attacks on those activities. I am not sure whether this is a manifestation of the lack of communication between what C. P. Snow described as the "two cultures"[1]—the culture of science and the culture of the humanities—or whether criticism of government science is really misplaced frustration with political leadership. Certainly, many people dealing with the day-to-day care of AIDS patients are frustrated that the government has not done more in terms of health care delivery, but this is not the area for which scientists are responsible. We need to examine public understanding of science and how it affects expectations of what scientists can and should do.

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[1] C. P. Snow. *The Two Cultures and the Scientific Revolution*. (NY: Cambridge University Press, 1963).

Social and Biological Origins of the AIDS Pandemic

Bernardino Fantini, Ph.D.

I am glad to have this opportunity to illustrate and discuss the research program on the history of AIDS carried on in Rome. The aim of this project is to apply to this topic three different methods we have already exploited in recent years. The first method is the possibility of studying past epidemics using the biological, medical, and clinical knowledge available today. The second is the concrete application to historical cases of the concept of pathocenosis first introduced in 1969 by Mirko D. Grmek. The third was applied by my research group in Rome on the history of malaria in Italy. It combines analysis of the biological, zoological, and medical research conducted from the 1870's to the 1940's with reconstruction of the socioeconomic structure in a broad cultural context, with particular emphasis on health education. The starting point of our research on the history of AIDS is a book by Mirko D. Grmek, published in French at the beginning of 1989.[1]

An epidemic or pandemic depends on three factors: (1) the biology of the infectious agent, (2) human biology, and (3) ecological and social conditions. There are two main questions in which we as historians are interested that also have practical consequences. The first is: In which sense is AIDS a new disease? The second is: Why now? A disease can be considered as new in at least five different historical situations. In the first, the disease existed before its first description, but it was hidden to medical knowledge, owing to the lack of conceptualization. Second, the disease existed before, but it was noted only when a sudden qualitative or quantitative change took place. Third, the disease did not exist in a given area but was introduced from outside. Fourth, the disease did not exist in any human population, but was present in animals. Fifth, the disease is absolutely new in the sense that its pathogenic agent did not exist as such before the first clinical evidence, which indicates the transformation of a preexisting nonpathological germ. From many points of view, the AIDS pandemic is necessarily a new disease; the pathology could not even exist as a concept before the recent discoveries made by molecular biology and immunology.

A disease is defined either from clinical signs or from pathological lesions—a morphological change in a tissue, a cell, or a molecule. From this point of view, there are many problems with the definition of AIDS as a disease, not only as a syndrome. In fact, people infected by HIV suffer signs and lesions typical of other diseases, and those were the only realities that could be observed 20 years ago. From this point of view, AIDS is certainly a new disease in its present epidemiological distribution.

The discovery of a second AIDS-related virus, HIV-II, has eliminated the possibility that the virus could have been produced by a single mutation in recent times. It is difficult to believe that two independent parallel mutations occurred at the same time, exactly when biology acquired the conceptual and technical means to identify and isolate the pathogenic human retrovirus. We think that HIV probably existed in the past but was hidden by the high incidence of infectious diseases. Examining abnormal increases in the frequency of a particular infectious disease may thus be a way to detect the presence of the virus in the past.

The AIDS pandemic is probably the consequence of the production of a new and virulent strain of a pre-existent germ. This should not be considered a historical accident, given the power of recombination of viruses, and of retroviruses in particular. In the past, however, such a highly virulent strain would have been rapidly eliminated, because the opportunistic infections it permitted would have been fatal to its hosts. An equilibrium exists between the virulence of a germ and its transmissibility. Virulence is a successful evolutionary strategy only if transmission rates are very high. Owing to the high frequency of infectious diseases, past AIDS epidemics would have been necessarily episodic and limited.

Evolutionary selection tends in the long run to favor the survival of both a virus and its host. There are many well-known examples in rodents and in chickens. A virus-host relation can change, however, and understanding how this might have happened in the case of AIDS may reveal many ways to control the virus. An extreme example of this equilibrium is an infective bacteria population in the test tube. Sometimes, a thriving bacteria population undergoes a catastrophic wipeout, and the bacteria will be succeeded by a much larger population of viruses, whose own fate is now problematic because they have exhausted their source of survival within that test tube. The culture medium in the test tube offers more chemical and physical barriers to virus transmission than does the space between people, but the biological principles are the same. In historical local epidemics of AIDS, this may have happened, but both the infected host and the viral parasites would have disappeared. Even the death of a single infected individual in the case of low transmissibility is disadvantageous to the virus, because a living host remains free to spread the virus, and this is what happens during the long latent phase of AIDS.

Viral or bacterial infections have destroyed large herds of animals, usually leaving a few immune survivors. This is also the most plausible mechanism for episodic shifts in population density. There are many good examples. The latest one is rabies in wild animals in Europe. The best known examples in humans of evolutionary adaptation are the sickle cell and the beta-thalassemia traits in Africa and in the Mediterranean areas as an adaptation to malaria. The advantage of heterozygotes in malaria areas in the past is today exacting a high cost in sickle cell disease and Cooley's disease among the homozygotes. Evolutionary equilibrium thus requires paying some tribute, but also deriving some protection against small viral aggressions. Unfortunately, we cannot rely on such an equilibrium. Our defense mechanisms do not always work, and viruses do not always acknowledge what would serve the long-term advantage.

Our relationship with parasites is a continuing evolutionary process. One of the best historical examples of the disequilibrium of a microbic pathologic agent in a human population is the transformation of syphilis during the 17th century, after the first tremendous burst of syphilis in the 16th century that carried a high mortality. Because of the large number of deaths during the initial outbreak, syphilis was named the grand pox, as compared with smallpox, which killed fewer people. During the 17th and 18th centuries, the morbidity and mortality rates declined, and an equilibrium was reached.

I would argue that during the second half of the 20th century, the effective transmission of the virulent AIDS virus has been favored by the introduction of new ways of diffusion, such as blood transfusions, wider use of injected drugs, sexual promiscuity, and the increasing survival of infected people. The association of biological and social factors caused a breach in the wall erected by the presence of infective diseases in the past. We thus witnessed a catastrophic event, in the sense of the mathematical theory of catastrophes, which passed the point of no return. To help explain the historical development of the AIDS pandemic, it could be useful to apply the concept of pathocenosis. Since, in a given historical population, different diseases are in equilibrium, the frequency of any disease depends on the frequency of the other diseases, in addition to endogenous and ecological factors. There is a historically determined equilibrium in the frequency of a disease in a population, each population having a small number of very frequent diseases and a large number of rare diseases. Thus, historical studies on specific diseases should take into account the history of the other diseases observed in a population. From this point of view, much work in historical pathology should be done. Our hope is that the spread of HIV and the AIDS pandemic might be better understood after the reconstruction of the past pathocenosis and the upset in the equilibrium.

Note

1. Mirko D. Grmek. *Histoire de Sida: Début et Origine d'une Pandémie Actuelle.* Paris: Payot, 1989; idem, *History of AIDS: Emergence and Origin of a Modern Pandemic*, translated by Russell C. Maulitz and Jacalyn Duffin. Princeton: Princeton University Press, 1990.

Discussion

Participant: The first instance of AIDS was reported as occurring in 1959, based on testing of serum from a glucose-6-phosphate dehydrogenase (G6PD) study. Does that agree with your knowledge about the origins of AIDS?

Speaker: No. The first case could have been in 1959, but the evidence is not conclusive. As is clear from genetic studies, the virus is at least 200 years old; thus, local epidemics of AIDS could have existed in the past and could be detected by careful examination of the increase in the frequency of particular infectious diseases.

Participant: A group of geographers recently met to address causes of death in uneducated populations. Given the problems of knowing why people die in many countries in this world, it is hard to trace the history of, and identify the newness of, disease.

Speaker: That is right, especially for the African countries, but we have many medical records in European countries that should be studied from this point of view.

Participant: Your mention of sexual promiscuity reminded me of comments about some of the early people diagnosed with AIDS in New York and San Francisco. They were homosexual men who were extraordinarily health-conscious. They "worked out," were physically active, and ate healthy diets. Yet their incidence of sexually transmitted diseases was very high. This suggests to me that people have a compartmentalized concept of what health means.

On the one hand, health means being physically active, being aware of diet, not smoking, limiting drug use. On the other hand, infectious disease is not considered to be a health issue. I think that we may need to look deeper at labels such as "sexual promiscuity" or "high-risk behavior" and examine concepts of health among different populations and how these ideas affect the way they live their lives.

Speaker: You are right. But from a biological point of view, sexual promiscuity is without doubt a reason for the spread of AIDS. It is clear from quantitative studies.

Commentary

Jack Pressman, Ph.D.

The central question underlying this workshop is: How did the great apparatus of modern clinical and laboratory science come to bear on the problem of what we now call AIDS? This question resonates with several "hot" issues in the history of science and medicine.

One area is the field of science studies, exemplified by the work of Bruno Latour and others. How is power established within a laboratory? How does that knowledge radiate outward? How does knowledge become generated in such remote settings and then become active? How do scientists, in a sense, step out of their laboratories and focus on real-world problems? A second area receiving attention is the cultural history of medicine, with a focus on the construction of the disease concepts themselves. How do diseases become visible, and what do they represent and symbolize? In this area of studies, clinical experience and social perceptions merge.

As the AIDS history industry increases, we will have to be explicit about such historiographic issues, about what we expect to learn from these studies. David Musto used the metaphor of how historical research puts a "spotlight on heretofore undisturbed areas." In his own example of running through Klebs' dusty papers, the metaphor was literal. Let me point out that an opposite effect also occurs. In recounting the story of AIDS, the spotlight is also being thrown back onto historians in an unprecedented way. Musto himself has had this "hot spotlight" put on him on "Nightline" and other TV shows. His face may be familiar to you. I am not being facetious—there is a recursivity at work here, as the observers themselves become observed and become subtly shaped by the objects upon which they focus their attention. (In trendier circles, the "clinical gaze" of Foucaultian terminology might arise.) Here, historians are conspicuously emerging from their own laboratory of archives and are trying to make their laboratory of knowledge directly *useful.*

My comments today have to do with the frameworks within which we approach this problem. AIDS history is blazing the trail of how we approach contemporary history of medicine, in particular, the history of scientific medicine. We have to separate out what is *special* about this disease as opposed to other diseases, health issues, or scientific issues, because it is going to be setting the stage for further studies.

First, it is difficult to work on projects in which the story is not yet over. For example, we wish to track laboratories around the world, yet we do not know which one is going to make the great breakthrough. If we try to do the history of *all* science related to AIDS research, we must read and understand several thousand articles. How, then, do we begin to hedge our own bets and decide which lines of research to follow?

In another sense, however, the story is assumed to be over. The rapidity with which the etiology became known and diagnostic procedures developed is unprecedented. It even led one historian to characterize AIDS as the first "postmodernist" disease. We *already* know; we have the answer; we can move on. As historians, however, we resist viewing AIDS as merely another triumph story within the infectious disease model. Interesting issues, for example, arose during the earliest period of AIDS, when scientists were struggling to understand its etiology.

The second issue concerns how the disease was first perceived in the clinical domain. We find that the patient was constructed in a fragmented manner, and seen within diverse clinical contexts. How did we first see this problem? We now know AIDS to be a masked disease. That is, it was making itself visible only through other diseases. It was a *meta disease*, one very difficult to decode.

The post-World War II history of science and medicine has been characterized by great shifts in scientific and clinical medicine. We have familiar historical frameworks in which to analyze the evolution of knowledge factories and knowledge production. For example, as suggested by the history of science literature, we might look at industrial laboratory contexts as opposed to academic research, or government-supported research as opposed to private philanthropy. In the 1970's and 1980's, however, these models merged. Academic environments such as the University of California, San Francisco (UCSF), where our Department of History of Health Sciences resides, have been described as having undergone a Balkanization. We have a collection of very powerful research institutes that adapt quickly to funding shifts and do not necessarily encourage disinterested scholars protected by their tenured appointments. In one department, there might be 80 faculty members and 2 tenure tracks. It is a different world.

These are problems that face Drs. Harden, Hammett, and Gross in attempting a local institutional history. We now have large conglomerates, huge empires. How do we qualitatively shift our own research to deal with these problems of scale? In a sense, we are almost becoming diplomatic historians. We have nation states in scientific medicine.

The clinical world, too, has shifted, undermining our familiar historical models and questions. For example, what has happened to the prerogative of the individual physician in experimenting with different treatments? Malpractice has changed the way physicians work. Who is setting the standards for what physicians can try? Physicians in the 1940's tried one type of drug, then another, and published simple tallies. This was a far cry from the controlled clinical experiment, which really is a post-World War II phenomenon.

The relationships between clinicians and the laboratory world have also become far more complex. Trying to pin down the location in which clinical research is going on is problematic today. With huge data bases and huge abstracting literatures, any medical library now has quick access to knowledge as it is generated around the world. How do we localize where the story is taking place, and how do we follow the communities? The first reports on AIDS contained long lists of clinicians and laboratory researchers representing many different disciplines. How do we determine today which discipline is the center of the action?

Today we have subcommunities within the clinical world. For example, subpopulations of homosexuals may go to particular physicians known to treat mainly homosexuals. How did these localized contexts affect the disease when it was first seen? Very different levels of knowledge and experience exist as we shift about in this fragmented and differentiated world of clinicians and laboratory investigators, whose interactions with patient subpopulations is extremely diverse. The actual experiences with patients constitute a very different knowledge basis.

Finally, experimentation itself has changed. It is difficult to run good controlled experiments in the new postmodernist world, where people are so educated as to what experiments are about, and where we have an obligation to terminate an experiment as soon as the therapy appears to be efficacious. If one can't run a trial to its end, how then *can* one test it? If suspicions arise that the trial was flawed, how can one run a new control to test that suspicion?

A thriving underground market now exists, winked at by authorities, of experimental drugs that have not made it onto the approved FDA lists. We see that communities have become far more powerful in determining and controlling their own treatment.

What kind of lessons do we hope to draw as we approach AIDS history, a history that is going to be the first to deal with modern health care in a concerted and powerful way? This history will set the stage for more general issues that we will also have to understand and come to grips with.

We may learn that there have been fundamental changes in the way the American public supports science. Much of the study of history of medicine in the 20th century focuses on how the acute disease model was built, empowering the profession of medicine and building support for laboratory science in the process. There is a reciprocal legitimization that goes on between the clinical and laboratory worlds. Laboratories, in the end, justify the monies pumped into them by demonstrating that someday they will be useful for targeted problems.

Clinicians, on the other hand, validate that they should be trusted as authorities because of what is being done in the laboratory. Relations within the profession can get testy. Laboratories dealing with real-world problems will argue that there are no good data available and that the laboratory perspective must be trusted as the best interpretation and guide to further research. Clinicians, however, argue that the types of answers that they get from the laboratories really do not pertain to real-world problems, but rather are laboratory artifacts, or "hothouse" solutions.

Yet the two domains present a united front to the public. Some of the public's frustration over how the scientific establishment has responded to AIDS derives from expectations of this model that has been built during the century. Dr. Schechter demonstrated this expectation that society has in the combined clinical and laboratory model. How, then, is the model going to change in light of the sting of AIDS? This is another way in which the history of AIDS is open-ended.

Finally, as Professor Fantini's paper showed, we now have much more complex ideas about how diseases actually work. Human ecology—relationships between human populations and their environment—is now turning inward. We are gaining understanding of the inner ecology of our bodies. The social science understandings of disease are thus becoming much more powerful and relevant. In sum, the task of writing AIDS history is a humbling challenge. From here on out, our studies necessarily must be interdisciplinary.

Workshop 2
Summary of Small Group Discussions

Historians should examine the impact of AIDS on biomedical research. Will research be skewed toward AIDS to the detriment of other disease problems, or will other disease problems benefit from the infusion of AIDS research funding? This question, raised by many people concerned with shaping research policy, should lead historians to a larger issue: How is biomedical knowledge created and transferred between disciplines?

Historians must be aware of changing definitions of AIDS and concepts related to AIDS produced by biomedical research findings. The initial description of this apparently new disease was as a "syndrome"—the "S" in AIDS—characterized by the onset of particular opportunistic infections or Kaposi's sarcoma. The term "AIDS-related complex" (ARC) was formulated to designate a less severe disease category. With identification of an etiological agent, the terms "HIV infection" and "HIV disease" also became widely used, and after a diagnostic test was developed, the concept of "seropositivity" was introduced. Historians need to establish clearly how these definitions were constructed and to examine the changing implications of each.

Better conceptual tools are needed to understand the complex nature of the AIDS pandemic and other epidemic disease events. Historians must employ concepts from a variety of disciplines and must collaborate across disciplines, when necessary, to understand the evolution of scientific knowledge relating to AIDS and how it was applied in the clinical response to people with the disease.

Both public and academic historians need to be involved in writing about government's response to AIDS. The differing viewpoints of public and academic historians will enrich the contemporary historical record of AIDS. Public historians should also become advocates for adequate government documentation of AIDS activities and should collect oral histories that will be available to all scholars. Accurate chronologies prepared by historians in both sectors will also provide a valuable framework for later scholars.

Historians should elucidate the roots underlying current activities relating to AIDS. Skill in revealing how these roots are intertwined is one area of expertise that sets historians apart from other disciplines. Suggestions for particular topics needing study included:

- internalist histories of research areas relating to AIDS, to illuminate why medicine was "ripe" for seeing the mechanism of AIDS as we understand it now.
- changing public perceptions of medicine in the 20th century, to provide context for public reaction to biomedical findings about AIDS.
- the shifting matrix of conceptions about sexuality, in which perceptions of AIDS among homosexual and heterosexual communities were embedded.
- public perception of and utilization of medical technology, to answer questions about AIDS testing policies. For example, did the experience with nonprescription home pregnancy testing kits contribute to policy discussions about possible marketing of nonprescription AIDS test kits?
- public expectations about technological intervention against disease, which framed societal response to research strategies against AIDS.
- the role of the media in interpreting medicine to the public, to illuminate public expectations of what medicine could accomplish against infectious diseases.

The number and scope of research programs in the field of history of medicine should be increased. Historians have many histories to write: the histories of diseases themselves, the history of the clinical response to diseases, the history of knowledge about diseases, the history of public health services, the history of scientific institutions involved with AIDS research, and the history of the social and psychological relation to diseases. The histories of scientific knowledge and scientific creativity cannot be separated from their institutional, political, social, and economic contexts. Achieving an accurate picture will require more workers in the field.

Evening Session

Introduction

William H. Helfand consults with the National Library of Medicine on its collection of public health posters. Recently, Mr. Helfand and the Library made a concerted effort to collect posters related to AIDS.

Images of AIDS: The Poster Record

William H. Helfand

In the last 5 years, an industry has emerged to bring intelligence about AIDS to the general population, and principally to particularly vulnerable groups: the homeless, homosexuals, residents of inner cities, and intravenous drug users and their sexual partners. Messages are carried through radio, television, films, articles in the press, brochures, advertisements, and posters. Posters are only one medium used to communicate facts, warnings, and suggestions for alternative behavior to elude this still-incurable syndrome. An analysis of the published record of AIDS posters reveals a great deal about the attitudes of society toward problems inherent in combatting this devastating illness.

Government health agencies throughout the world, and private associations in almost all the affluent nations, have been publishing posters on AIDS since the early 1980's. Not surprisingly, these posters show national and cultural differences. Further, the poster record reveals the diversity of directed approaches to specific segments of the population. Despite these variations, posters are clearly not capable of reaching everyone with their messages. Nonetheless, a study of poster campaigns is indicative of contemporary attitudes to the AIDS crisis.

As a form of public communication, posters are ephemeral—here today and gone tomorrow. When posted on the walls of buildings, they are subject to the weather, and when placed on bulletin boards in offices, bus stations or hospitals, they are easily replaced. They have poor staying power. Because of this, it is extremely difficult to reconstruct material used in educational campaigns in past epidemics. For example, it is today almost impossible to locate examples of posters published as part of the 1975 swine flu campaign during Gerald Ford's Administration, for although they were ubiquitous, very few of the many cartoons, brochures, posters, booklets, badges, or other printed ephemera appear to have been preserved.

Recognizing this fact, the National Library of Medicine (NLM) has recently begun a program to collect representative samples of public health posters, as a major communications medium, to provide a resource for future use. This program will clearly be of value for future researchers studying methods used to sensitize public response to AIDS during the 1980's. In deciding to accumulate this material, NLM was not interested in AIDS alone. The intent of the poster program since its inception at the end of 1987 has been to search for examples of posters for all health and related biomedical issues, AIDS being the most significant at the moment, but not the only serious public health matter of worldwide concern. In its quest for representative examples, the NLM poster program contacted more than 4,500 public and private agencies, and by the end of February 1989 had assembled more than 2,500 posters covering a broad variety of public health issues, including scabies, alcoholism, head lice, sunburn, breastfeeding, and nutrition. The program continues to grow in importance.

Since the NLM program began, the public health issue for which the largest number of posters has been accumulated is AIDS. There are more than 1,000 agencies in the United States alone dealing with the AIDS problem. They include the Public Health Service (PHS), state health departments, and civic, religious, homosexual, and fraternal organizations.[1] The United States and most European countries are exceptional among the nations of the world in having private organizations as well as governments interested in spreading the word about public health matters. In the majority of countries, publication of such material is the responsibility of governments alone. In Africa, South America, Asia, and Eastern Europe, government posters state the official positions and priorities in public health communications. This is not to say that government posters are inferior because they are official, for there are some very creative and valuable posters emanating from government groups.

Of the first 2,500 posters cataloged in the NLM collection, more than 350 deal with AIDS in one way or another. Not surprisingly, several ideas used in the past for other public health issues appear with only minor modification in AIDS campaigns, and it is interesting to note the variations artists and designers use in treating similar concepts. At the same time, there is a boldness rarely seen until the present, as the impact of AIDS and drug abuse has entered the public consciousness.

Posters are a relatively modern means of communication. There were European broadsides as early as the 15th century, to combat epidemics such as plague and cholera, or to propose measures for improved sanitation, but these were not illustrated. A plague sign, showing two crosses above the word "pest" was used on doors of homes in Ehrfurt, Germany, in the 17th century, but such ephemera have almost no chance of survival and are rarely seen in museum collections.[2] Illustrated posters began to appear during the 1840's, when technological advances in the use of large-scale machinery permitted publication of lithographs in more than a single color. The earliest posters were for commercial products, and it was not before the beginning of the present century that posters for public health matters began to appear.

Most posters dealing with AIDS present information or propose that the reader seek out pertinent facts. For example, an Australian poster lists five groups of statements: who gets AIDS, what AIDS is, how one gets AIDS, what will not lead to AIDS, and how one can be safe (see Figure 1). Many posters present similar facts, varying only in the amount of detail and in the graphic treatment of information. Factual posters have always been a primary theme in public health education. A French poster illustrating proper procedures to prevent tuberculosis is a good example. The Rockefeller Foundation, recognizing the trauma of the abnormally high incidence of tuberculosis in France in the years after World War I, sent teams to disseminate educational materials to the French.[3] They tried to give the populace specific facts about tuberculosis and its treatment. French poster artists were employed to create both posters and post cards; these were distributed liberally at meetings and conferences to help audiences understand what could be done about tuberculosis.

Twenty-one posters came out of this effort, of which one poster with 12 small illustrations was probably the most used.[4] It shows how tuberculosis is communicated and what precautions one should take against tuberculosis. Today, with nearly insurmountable problems, such factual posters remain in the forefront in bringing educational messages to the public about AIDS.

Variations on these informational posters stress the risks of fatal consequences if the facts are ignored; they caution people about the insidious nature of AIDS. They either state the warning explicitly ("AIDS is a killer") or they use striking graphic images to communicate the same message. The combination of information with potent imagery makes for memorable and effective designs.

To allay fears and misconceptions, another group of information posters explains what will not cause an AIDS infection. A recent campaign among school children in Alaska developed a number of useful ideas, among which was one poster of a magnified mosquito, with the headline "Go Ahead! Spread the Word! You Can't Get AIDS From Alaska's State Bird!" Another popular poster used throughout the United States attempts to quell commonly expressed fears, illustrating a handshake, a doorknob, a toilet seat, and a table setting, pointing out that "None of These Will Give You AIDS" (see Figure 2). This approach is similar to past campaigns to quiet fears by pointing out what would and what would not cause cancer. Such posters also bear some affinity to those that in the past distinguished proper from improper treatment.[5]

Finally, certain informational posters propose that the reader call or write for more complete information. These merely suggest the importance of obtaining information, without specific detail. The AIDS Action Committee published a poster with the message "Get the Facts," the illustration repeating the word "ask" in a variety of typefaces and sizes. A telephone number was provided for viewers to follow the notice. Related posters promise a booklet that will be sent through the mail. These efforts rely on striking graphics to grab attention, rather than on important messages. One never knows, of course, whether compelling graphics are sufficient tools for effective communication. To be sure, the first requirement of a poster is to communicate. Its effectiveness depends on getting the reader to do something in response to its message, to purchase something or to change a pattern of behavior.[6] Some are better than others at moving people to take action. The fact that posters continue to be used widely in all countries and in all cultures confirms that they produce some positive result.

Celebrities, including artists who might not normally be associated with so serious a problem, have been marshaled to aid in AIDS communications efforts. A Norman Rockwell illustration of a father giving the "facts of life" to his son, contains an added warning, "Don't Forget the Chapter on AIDS." The popular rock singer Patti LaBelle appears in a poster published by the American Red Cross urging viewers, "Don't Listen to Rumors About AIDS; Get the Facts" (see Figure 3). Certainly, the idea of using celebrities in posters is not new, for the technique was frequently employed for public health problems in the past.[7]

Another category of AIDS posters relies on emotional imagery to elicit fear. Gravestones or, more frequently, skulls and corpses, convey stark warnings on the importance of avoiding exposure. A Mexican poster shows a morgue as the setting for a corpse. Only the victim's feet are visible, but the message is clear nonetheless. The headline, "El Riesgo Es De Todos" (the risk is death) is perhaps superfluous (see Figure 4). Similarly, a poster by the Pharmacists' Planning Service of Sausalito, CA, shows a row of gravestones with the caption "People Are Dying to Know." A poster from the Pan American Health Organization (PAHO) shows an anguished figure filling the spaces in the word SIDA (AIDS). The figure is clearly scared. Why he should be scared and what the viewer should do to prevent being in the same state are the essential messages of the poster. The text demands simply that one get the necessary facts, and to the extent that the graphics are effective, the reader will.

The most powerful posters in this fear-inspiring category use an image of a skull. For example, a Spanish-language poster, "El SIDA," published by the Nipomo, CA, Community Medical Center, has a line-drawing of a skull with a syringe in its mouth. The text tells what AIDS is, how one gets it, and what must be done to avoid it. But the image of death does not need extensive text to convey its message.

Such images have a long history. One of the most memorable in this group is "L'Hécatombe–La Syphilis," a poster by Louis Raemakers, a Belgian artist whose posters are widely collected. The frightful smile on the face of the woman standing in a field is reinforced by the skull she holds at her waist.[8] A skull also appears at the bottom of a World War I poster by Théophile-Alexandre Steinlen, showing a soldier talking to a prostitute, and later, sitting alone in a hospital ward. Its message is clear, and a grinning skull surrounded by barbed wire at the bottom adds to its impact.[9] It was neither necessary nor advisable for Steinlen to mention the word "syphilis"; at the time of the poster, this was not a word to be expected in polite discourse. The skull appears often in such venereal disease posters; those by the French artists Mauzan and Théodoro effectively employed the same symbol.[10, 11] It even carried to posters of World War II, as shown by an example of the British artist, Reginald Mount, "Hello Boy Friend Coming My Way?"[12] The Mount poster, as well as a large group of earlier venereal disease posters, share a common theme—that it is the woman who is responsible for infection and that contact must be avoided at all costs. Such "Juke Joint Snipers," are not to be trusted, and even the girl-next-door who "may look clean, but" is the one who has been the cause of the problem.[13, 14] While such posters have been characteristic of earlier venereal disease campaigns, they have not surfaced significantly in the United States and Europe, where heterosexual transmission of AIDS, other than among intravenous drug users, is still considered a minor factor. In Africa, however, where it is the major route of transmission, we do have posters warning men to watch out for easy sexual partners; an example from Mauritius uses cartoons to illustrate the point (see Figure 5). As heterosexual transmission grows in importance, especially in inner-city areas, we can expect to see more posters with similar subjects. It is doubtful, however, that we will ever reach the hysterical stage of World War I campaigns, in which slogans such as "Dames and Rum Don't Mix" or "A German Bullet is Cleaner Than a Whore"[15] were used.

Death, personified by a skeleton or skull, has long been a powerful metaphor for artists in presenting public health issues, and it has been used frequently beyond the field of venereal disease. For example, an Italian tuberculosis poster by T. Corbella reviews the methods by which the disease will be conquered, using perseverance, temperance, sunshine, hygiene, fresh air, and rest.[16] Corbella's image, as in most posters using this idea, is a powerful one. More recently, the American graphic designer Milton Glaser was asked to design a symbol for AIDS for the World Health Organization (WHO), and his variation also uses a skull—a universal, easily understood symbol in all languages, and an excellent choice (see Figure 6).

While most posters in AIDS campaigns are designed by graphic artists such as Glaser or by anonymous design studios and photographers, several well-known artists have also developed poster images. Of course, artists have been involved in drives to raise money for AIDS research and patient care, and there have been exhibitions of the work of filmmakers, photographers, painters, and sculptors on AIDS subjects, but with minor exceptions, popular artists have not been commissioned to design posters for AIDS.[17] Paul Davis, the artist responsible for memorable campaigns for the New York Public Theatre, published a poster to raise money to benefit the East End Gay Organization in East Hampton, New York. The image, however, is not specifically related to AIDS. A widely distributed poster for its AIDS activities was created for the Student Health Service of the Berkeley campus of the University of California by the well-known San Francisco artist, David Lance Goines. The illustration of a snake and an apple has implications on transmission of the virus, and Goines' poster created some controversy when it first appeared (see cover illustration). The use of the snake also has had antecedents in public health posters; one striking example is the 1900 poster by the Spanish artist Ramon Casas for a sanitarium promising a cure for syphilis.[18] In the design, a woman seems unaware of the small snake crawling up her back as she gazes into the distance. To be sure, it is a vexing problem for an artist to visualize disease, and over the years snakes, monsters, crabs, crustaceans, bombs, magnified microbes, and extraterrestrial beings have been employed to convey illness.[19] A good example against tuberculosis is an Italian poster by Basilio Cascella in which a nurse uses her small dagger to attack the ferocious monster representing the disease which has managed to encircle half the globe.[20] Another Italian poster, against malaria, uses the metaphor of planes and bombs attacking the populace with their infectious agents.[21] For AIDS, the problem is just as perplexing as always, for no one has developed a way to illustrate HIV effectively.

In the continuing drive to reach as many people as possible with messages on AIDS prevention, poster campaigns have been developed to appeal to specific groups. Such market segmentation has been an important technique for commercial products and has been found useful in the public health field as well. The People of Color Against AIDS, an organization in Seattle, WA, states that "AIDS is a White Man's Disease" in one of a series of posters entitled "Famous Last Words." Special campaigns are directed to those who have many sexual partners. An example from Fiji urges readers to believe that casual relationships are just not worth it, or that, as a poster from the island of St. Kitts suggests "You're Safer With One Partner" (see Figure 7). A Philippines poster directed to prostitutes reminds them to provide condoms for their clients (see Figure 8). Special campaigns are also directed to women of childbearing age, urging them to be tested before becoming pregnant. While these posters have great impact, especially the series carrying the title "She Has Her Father's Eyes and Her Mother's AIDS," there remains the problem of reaching that group of women to whom the campaign is directed, and then convincing them to take the required steps to be properly tested. These messages tell women who may have been exposed, or may be carriers of the AIDS virus, and who are thinking of becoming pregnant, to be extremely cautious. They clearly say "DON'T. You read about people who can carry the AIDS virus but show no symptoms; don't take chances. Get tested before you become sexually involved" (see Figure 9). Despite all the educational campaigns, however, the number of children born with AIDS regrettably continues to grow.

The American poster of the appealing baby with "Her Father's Eyes and Her Mother's AIDS" exists in versions showing a black child as well as a white child. Similarly, posters of intravenous drug users repeat the same copy in versions showing a black, white, and Hispanic model. And, there are posters of homosexual men—black, white, and Hispanic—directed to specific segments of the population. A series of posters published by the New Haven Mayor's Task Force presents telling photographs of men and women, black, white, and Hispanic, in English and Spanish, discussing the importance of practicing safe sex. These segmented campaigns are for American audiences, of course, but correspondingly, posters published in multilingual countries such as Canada, Belgium, and Switzerland have similar illustrations with different texts.

Another special target has been prospective blood donors. Widespread anxiety erroneously exists over possible dangers of becoming infected with the HIV virus by donating blood, and several posters have been produced to try to allay these fears.

Their aim is to stress safety and to reduce disquiet over possible contamination.

While most issues in AIDS posters have antecedents, there are several using completely new ideas. The seriousness and pervasiveness of the AIDS crisis have necessitated discussing subjects openly in ways that would never have been tolerated in the past. The use of condoms and the vital importance of safe-sex practices are categories of posters that are new, and are among the most forceful that have been developed. The intent of many of the condom themes has been to make their use a demystified, everyday event, worthy of no special attention. A Swiss campaign blends romance with condoms, using one as a substitute for the full moon, in settings over easily identifiable places—Hawaii, Paris, Rome, Rio, and London. The agency preparing these posters has made them in three sizes, the largest for outdoor billboards, and has also prepared stickers to be affixed to envelopes. Three Icelandic posters show ordinary citizens using a condom in unorthodox ways, playing with one, stretching one, blowing one up, using one as a head covering, etc. The photographs of the men and women used as models in these posters also carry their signatures; the posters imply that condoms will "Stop AIDS." The popularization of condoms has even spawned National Condom Week, as a poster published by the Pharmacist's Planning Service of Sausalito testifies.

The "Famous Last Words" series, distributed by People of Color Against AIDS, also includes a poster with the message, "I Don't Need to Wear One of Those," stressing the necessity of using condoms. And a British poster, widely used in airports and bus terminals, shows a condom with the headline "Life Insurance for 15p." From a distance, unfortunately, it is not possible to know what is being sold, and it is only on close inspection that one realizes it is a condom; the subtlety of the poster may well be lost on many passers-by. On the other hand, the couple embracing over the headline "Don't Die of Embarrassment; AIDS is a Killer. Use a Condom," seems better at holding the attention of the viewer. But, as with commercial advertising, it is only the proper blend of text and image that can provide an effective result.

Caricatures and comic strips have also been used to enhance the acceptance of condoms. The Ministry of Health of Australia has developed comic strip posters to stress the need for condoms in campaigns directed to the aboriginal community. In one, "You Don't Have to Be a Queenie to Get AIDS," a man has sex with someone who has AIDS. He goes back to his wife, She gets sick; she gets AIDS. Quickly, everybody gets sick and dies. This Australian campaign has even developed a poster with a new hero, Condom Man, who suggests that the viewer "Use Frenchies." The comic strip technique is an easy way to get attention; it was used in several venereal disease campaigns in World War II, in which blown-up images of brief episodes stressed the need to avoid prostitutes or, if this was not possible, to pay quick visits to the "pro station," where prophylactic condoms were dispensed.[22, 23]

Of course, posters used by the United States in World War II did on occasion discuss the importance of prophylaxis, but they never were so bold as to mention condoms. A series by the popular illustrator Arthur Szyk suggested that failure to use prophylactic measures was an aid to the enemy, and another poster carried the headline "Sex Exposure Without Prophylaxis is an Aid to the Axis," but condoms were neither pictured nor mentioned.[24, 25]

Homosexual groups have also emphasized the importance of using condoms in the practice of safe sex. The Gay Men's Health Crisis in New York has effectively used a drawing with text in both English and Spanish noting that "A Rubber is a Friend in Your Pocket." A Swiss poster shows condoms along with a watch band, a necktie, and other masculine apparel noting that this is the new intimate line for men. A large photograph of a condom has only the briefest text, in letters much smaller than the photograph, "Help Prevent Despair. Care." And HERO, a Baltimore group, has issued posters of homosexual men—black, white, and Hispanic—with the provocative headline, "You Won't Believe What We Like to Wear in Bed."

Expanding on the importance of condoms, a related category discusses safe sex in its various aspects. Again, many of the posters on this theme have been issued by homosexual groups. Two representative images by B. Rapp were published by Aid for AIDS, in Los Angeles, CA, with copy reading "Safe Sex. Are You Man Enough?" and were distributed throughout the state by the California Department of Health (see Figure 10). Another poster displays the muscular torso of a man with the copy "No Less a Man for Playing Safe." In their demand for attention, some posters directed to the homosexual community are extremely frank in discussing various sexual practices. For example, a poster by the Colorado AIDS Project promises that "Our Workshop is Positively Erotic," and another from the Tucson AIDS Project, parodying a title from a Paul Simon song, suggests that "There Must Be 50 Ways to Please a Lover," illustrating 16 of them. Finally, a large poster for the Colorado AIDS project, cleverly designed to be used either as one or as six individual smaller posters, proposes methods of practicing safe sex with the titles "Taste, Watch, Touch, Excite, Explore, Imagine," with appropriate illustrations and provocative texts for each.

A critical AIDS campaign is directed to IV drug users. The problem of reaching this group to stop this deadly practice is not an easy one to solve. A crudely drawn poster from the Brooklyn AIDS Task Force admonishes "Hey Man—No Sharing." Both Swiss and American posters have appeared with large syringes and needles as the illustration, with brief texts urging readers "Don't Pass It On" (see Figure 11). Other posters, especially those published by the British Department of Health and Social Security, are more striking and bold in attracting attention. One with the headline "Heads You Live, Tails You Get AIDS" is representative. These daring visual images do get the attention of the viewer, but the problem is to force those practicing the vicious habit of intravenous drug usage and the sharing of unclean needles to look at the poster in the first place. Even the most shocking illustration cannot guarantee that members of this hard-to-reach group will notice, for they may be completely resistant to any message at all. A dramatic poster in this group is a billboard-size advertisement issued by the U.S. Public Health Service that shows a skeletal hand noting that "Sharing Needles Is Just Asking For It" (see Figure 12).

A final theme in AIDS education efforts, and a relatively recent addition, asks that we show compassion for the patient with AIDS. Posters from the United States and from Germany make exactly the same point: "Don't Give AIDS a Chance," and don't leave the patient with AIDS to suffer alone. One of the strongest and most appealing in this group is that of a child: "I Have AIDS; Please Hug Me. I Can't Make You Sick" (see Figure 13).

Unfortunately, the NLM collection does not permit us to generalize about changes in content over time. Few of the posters against AIDS are dated, and few have the names of the artists and design studios who prepared them. Certain trends, however, are clear. In the United States now, a greater effort is being directed to minority groups, to the homeless, and to intravenous drug users. Greater efforts are being expended to reach those living in slum areas of large cities. Despite this, many posters in the United States are still directed to the homosexual community. In Europe also, publicity is beginning to address a broader segment of the population, but not to the extent that it has in this country. Third World efforts are still not as hard-hitting and bold as they are elsewhere, even though for those areas the problem is growing rapidly.

Despite the variety of appeals in the posters on AIDS, there is one concept that we might have expected and which does not seem to have surfaced as yet. None of the AIDS posters in the sample of 350 in this analysis shows a patient with AIDS. Why should this be the case? Are considerations of privacy and public sensibility sufficient to overcome the need to show the ravaging effects of the disease? Would it so offend the viewer that he or she would not wish to obtain further information? Patients with AIDS have been the subject of photographs by leading artists, most notably Nicholas Nixon, but the purpose of these photographs differs from that of the posters. New posters keep being created all the time, however, and their number will continue to grow as long as the AIDS problem remains, so that posters including illustrations of AIDS patients may well be included as time goes on. In any event, the existing large group of posters is clearly representative of the extensive worldwide educational efforts that have been mounted to direct attention to the catastrophic effects of AIDS. The archive of AIDS posters that the NLM is building can be only expected to grow in importance in the future.

Notes

1. Christopher S. Hall, ed. *AIDS Lifeline: AIDS Educational Service Organizations.* Washington, D.C.: National AIDS Network, 1988.

2. PEST, PEST. Anonymous woodcut, Germany, 1683. Ars Medica (Philadelphia Museum of Art) Collection. A quarantine sign, showing two crosses over the words of the title.

3. Nancy Tomes. *The Rockefeller Commission for the Prevention of Tuberculosis in France: A Comparative Perspective on American Health Reform.* Unpublished manuscript, 1989.

4. COMBATTRE LA TUBERCULOSE. Anonymous lithograph, France, c. 1920. Rockefeller Archive, NLM Collections. There are 15 small illustrations in four groups, showing how tuberculosis spreads, friends to combat it, its enemies, and precautions to take.

5. NO HOME REMEDY EVER CURED CANCER. Anonymous lithograph, U.S.A., c. 1940. Museum of Modern Art (New York) Collection. The illustration shows the head of a worried woman holding a teaspoon to her mouth. The full text reads "No home remedy, no tonic, no special diet, no salves, no powders, no pills ever cured. Only surgery, x-ray or radium can cure cancer." Published by the American Cancer Society.

6. William H. Helfand. "The Pharmaceutical Poster." *Pharmacy in History.* 1973, pp. 15, 2, 67.

7. L'HOMME LE PLUS FORT DU MONDE DECLARE ... Anonymous lithograph, France, c. 1935. NLM Collection. An illustration of the boxer, Charles Rigoulot, in a fighting pose. The text continues "le secret de ma force. Pas d'alcool." Published by the Comité National de Défense contre l'Alcoolisme.

8. L'HECATOMBE. LA SYPHILIS. By Louis Raemakers, Belgium, c. 1916. Ars Medica (Philadelphia Museum of Art); U. of Wisconsin Medical School Library Collections. A woman with spider-like hair, wearing a black cloak, stands among rows of graves. She holds a skull in her hands in this powerful illustration of the evils of syphilis.

9. SOLDAT. LA PATRIE COMPTE SUR TOI... By Théophile-Alexandre Steinlen, France, 1916. Ars Medica (Philadelphia Museum of Art), NLM Collections. The text is written on a tombstone, and presents a dramatic appeal to French soldiers to keep strong for their

country, and to resist those seductions in the street which risk exposure to an illness as "dangerous as war" leading to a "useless death without honor." The symbols are a woman embracing a soldier, a sick soldier in a hospital, a skull and crossbones, etc.

10. DOS INTRUSOS QUE, MUY A MENUDO, FORMEN PARTE DEL CORTEUO NUPCIAL. By Lucien Achille Mauzan, France, c. 1905. A bride and bridegroom are attended by two figures of death, one labeled "Blenorragia" and the other "Sifilis." Spanish text, the poster probably intended for use in Argentina.

11. LA SYPHILIS EST UN FLEAU SOCIAL. SES VICTIMES SONT INNOMBRABLES. By Théodoro, France, c. 1930. Ars Medica (Philadelphia Museum of Art) Collection. A man and woman kiss; behind them is a grinning skull. A lengthy text appears below the illustration, and a line at the bottom warns that each victim must be cured and avoid transmitting the disease to others.

12. VD. HELLO BOY FRIEND, COMING MY WAY? By Reginald Mount, England, c. 1943. The illustration is of a skull, with an orchid for a hat. Below the title and illustration is a lengthy text warning of the "easy" girl friend.

13. JUKE JOINT SNIPER. By Ferree, U.S.A., c. 1942. NLM Collection. A prostitute stands in front of a dance hall, lighting a cigarette. The title is on the top and at the bottom, the words "Syphilis and Gonorrhea."

14. SHE MAY LOOK CLEAN BUT. Anonymous lithograph, U.S.A., c. 1944. NLM Collection. The illustration is of a pretty woman, with three service-men walking by. The text continues: "Pick-ups, 'Good-Time' Girls, Prostitutes Spread Syphilis and Gonorrhea."

15. Allan M. Brandt. *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880.* New York & Oxford, 1985, 101.

16. CON QUESTE ARMI VINCIAMO TUBERCULOSI. By T. Corbella, Italy, c. 1920. Ars Medica (Philadelphia Museum of Art) Collection. Swords bearing methods to combat tuberculosis attack a hooded death figure. The measures, cleanliness, sun air, rest, proper food, hygiene, and perseverance assure that "...with these arms we shall conquer tuberculosis."

17. Michael Kimelman. "Bitter Harvest: AIDS and the Arts." *New York Times*, Section 2, March 19, 1989, p. 1.

18. SIFILIS. By Ramon Casas, Spain, 1900. Ars Medica (Philadelphia Museum of Art) Collection. A woman wearing a long, fringed cape holds a flower as a snake climbs up her back. The text advertises a sanitarium for the cure of syphilis; it reads "Sifilis. Curacion Absoluta y Radical en el Sanatario Para Sifiliticos...."

19. For illustrations of various methods by which cholera has been depicted, see P. Bourdelais and A. Dodin, Visages du Choléra, Paris, 1987.

20. ITALIANI, AIUTATE LA CROCE ROSSA NELL'ASSISTENZA AI TUBERCOLOSI. By Basilio Cascella, Italy, c. 1920. Ars Medica Collection (Philadelphia Museum of Art).

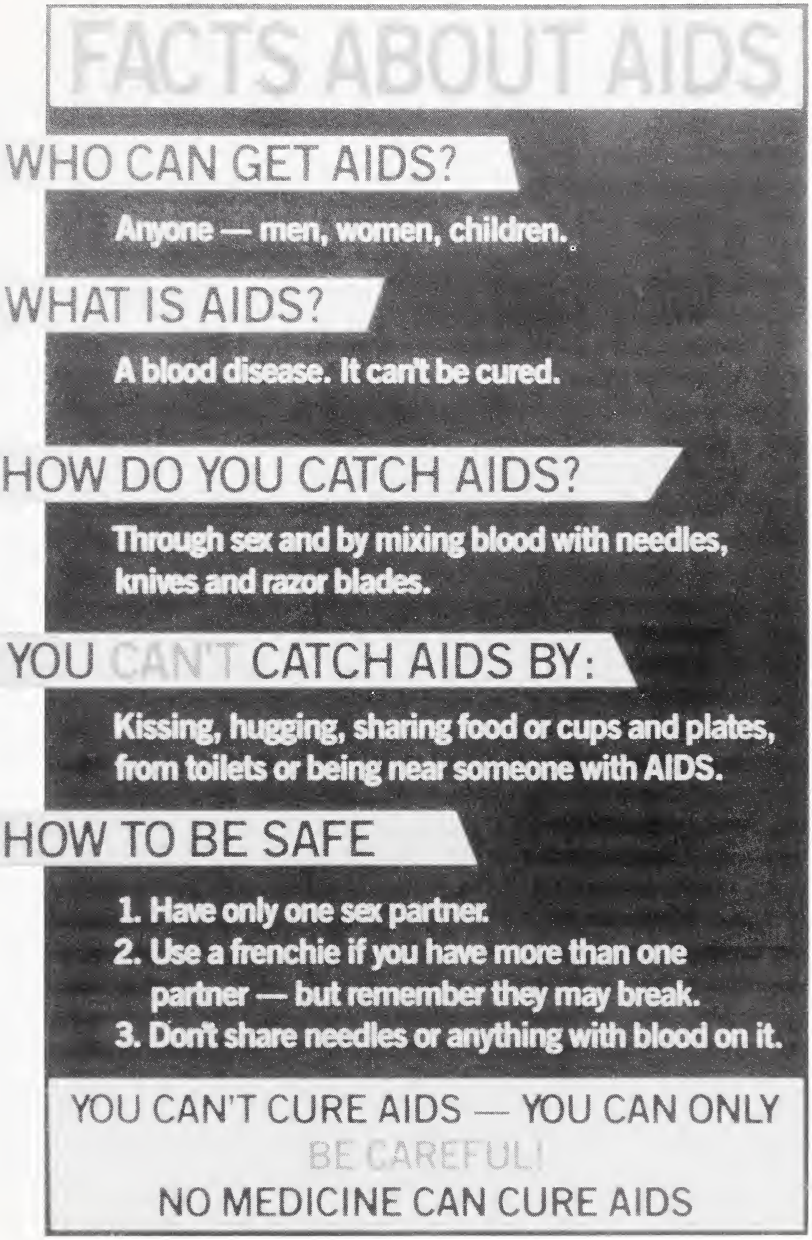
21. GUERRA ALLA MOSCHE I... Anonymous lithograph, Italy, c. 1920. Ars Medica (Philadelphia Museum of Art) Collection. A procession of flies, as airplanes, the first one holding a bomb labeled "Microbi" which it drops on a crowd of people. A second bomb is falling; it is labeled "Germi della Tisi," and a third, "Malatie," is breaking up.

22. PLEASE BE CAREFUL. By Woodcock, U.S.A., 1944. NLM Collection. A comic strip, in nine sections, warning sailors to use care to prevent infection from venereal disease. Published by Bureau of Medicine & Surgery, U.S. Navy, VP-7.

23. NOW, WHAT WAS I SUPPOSED TO REMEMBER? By Woodcock, U.S.A., 1944. NLM Collection. A forlorn-looking sailor asks himself the question of the title as he approaches a pro station. Published by Bureau of Medicine & Surgery, U.S. Navy, VP-8.

24. FOOL THE AXIS - USE PROPHYLAXIS. By Arthur Szyk, U.S.A., 1942. Helfand Collection. Mussolini, Tojo, and Hitler are shown, the latter two holding syringes. At the bottom "Prophylaxis Prevents Venereal Disease" and the note that the publisher is John Wyeth & Brother, Inc., Philadelphia.

25. SEX EXPOSURE WITHOUT PROPHYLAXIS IS A HELP TO THE AXIS. Anonymous lithograph, U.S.A., c. 1942. Helfand Collection. The illustration shows Hitler, Tojo, and Mussolini, who say "Thanks Friends!!" as they look at hospital beds in a "Venereal Disease Ward." At the bottom the text reads "Prophylaxis Prevents Venereal Disease."



FACTS ABOUT AIDS

WHO CAN GET AIDS?

Anyone — men, women, children.

WHAT IS AIDS?

A blood disease. It can't be cured.

HOW DO YOU CATCH AIDS?

Through sex and by mixing blood with needles, knives and razor blades.

YOU CAN'T CATCH AIDS BY:

Kissing, hugging, sharing food or cups and plates, from toilets or being near someone with AIDS.

HOW TO BE SAFE

1. Have only one sex partner.
2. Use a frenchie if you have more than one partner — but remember they may break.
3. Don't share needles or anything with blood on it.

YOU CAN'T CURE AIDS — YOU CAN ONLY
BE CAREFUL!
NO MEDICINE CAN CURE AIDS

Fig. 1. Facts About AIDS. An Australian example using text alone in presenting basic facts on the disease. (Courtesy of the National Library of Medicine Collection.)

Fig. 2. None of These Will Give You AIDS. Fear of four possible sources of AIDS transmission illustrated in one poster distributed by several AIDS groups in the United States. (Reproduced with permission of the Milwaukee AIDS Project. Courtesy of the National Library of Medicine Collection.)

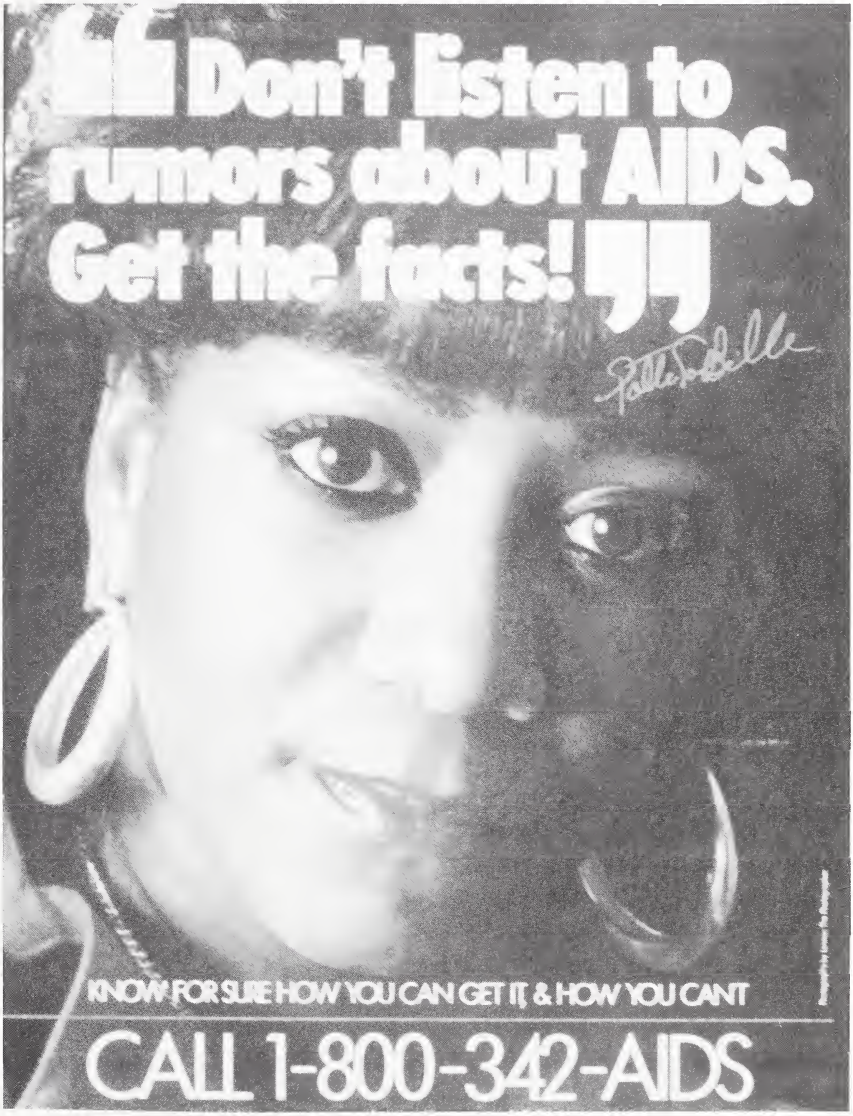


Fig. 3. Don't Listen to Rumors About AIDS. Get the Facts. The popular rock singer, Patti La Belle, in an American Red Cross drive to disseminate information about AIDS. (Courtesy of the National Library of Medicine Collection.)

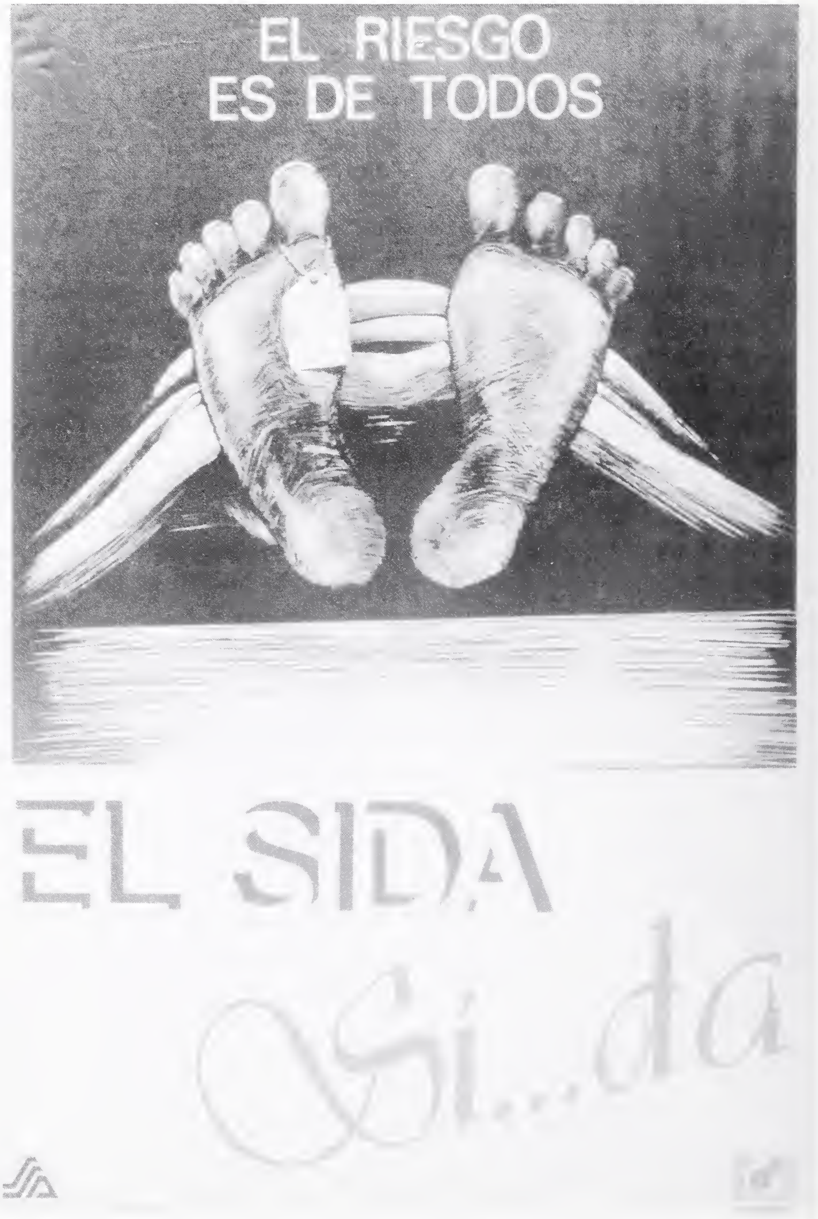


Fig. 4. El Riesgo Es de Todos. Fear is a major element in many posters warning about AIDS; this Mexican example relies on simple graphics to convey its deadly message. (Courtesy of the National Library of Medicine Collection.)

Fig. 5. Le SIDA. Evitez les Partenaires Faciles. A poster from Mauritius, a country where heterosexual transmission of AIDS is a major route, warning men against contacts with "easy partners." (Courtesy of the National Library of Medicine Collection.)

Fig. 6. AIDS. A Worldwide Effort Will Stop It. A poster developed for the World Health Organization by the New York designer Milton Glaser. (Courtesy of the National Library of Medicine Collection.)

Fig. 7. You're Safer With One Partner. The importance of minimizing casual sex is stressed in this poster from the Health Education Unit of St. Kitts. (Courtesy of the National Library of Medicine Collection.)

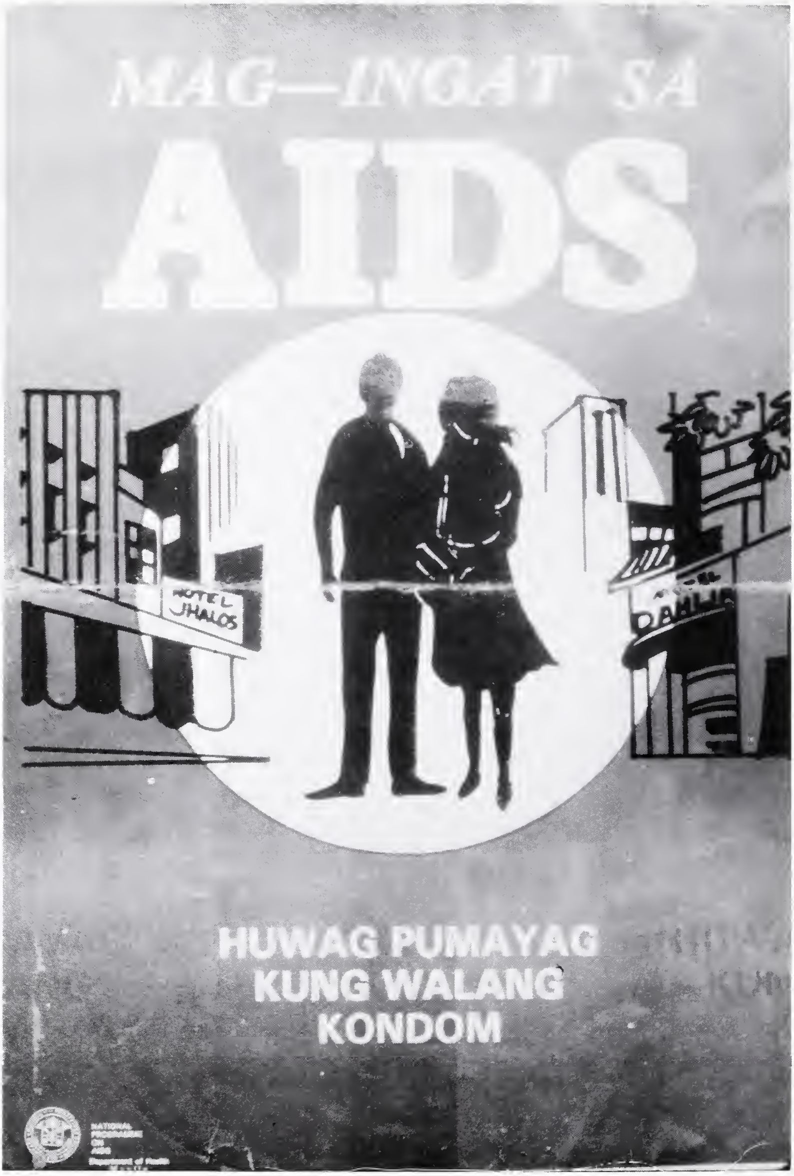


Fig. 8. Mag-Ingat sa AIDS. Health authorities in the Philippines mounted a special drive to encourage prostitutes to use condoms. (Courtesy of the National Library of Medicine Collection.)

Fig. 9. Don't Give AIDS to Your Unborn Baby. In this appeal to I.V. drug users, perhaps the most difficult audience of all to reach, the message stresses the need to be tested before becoming pregnant. (Reproduced with permission of AID Atlanta. Courtesy of the National Library of Medicine Collection.)

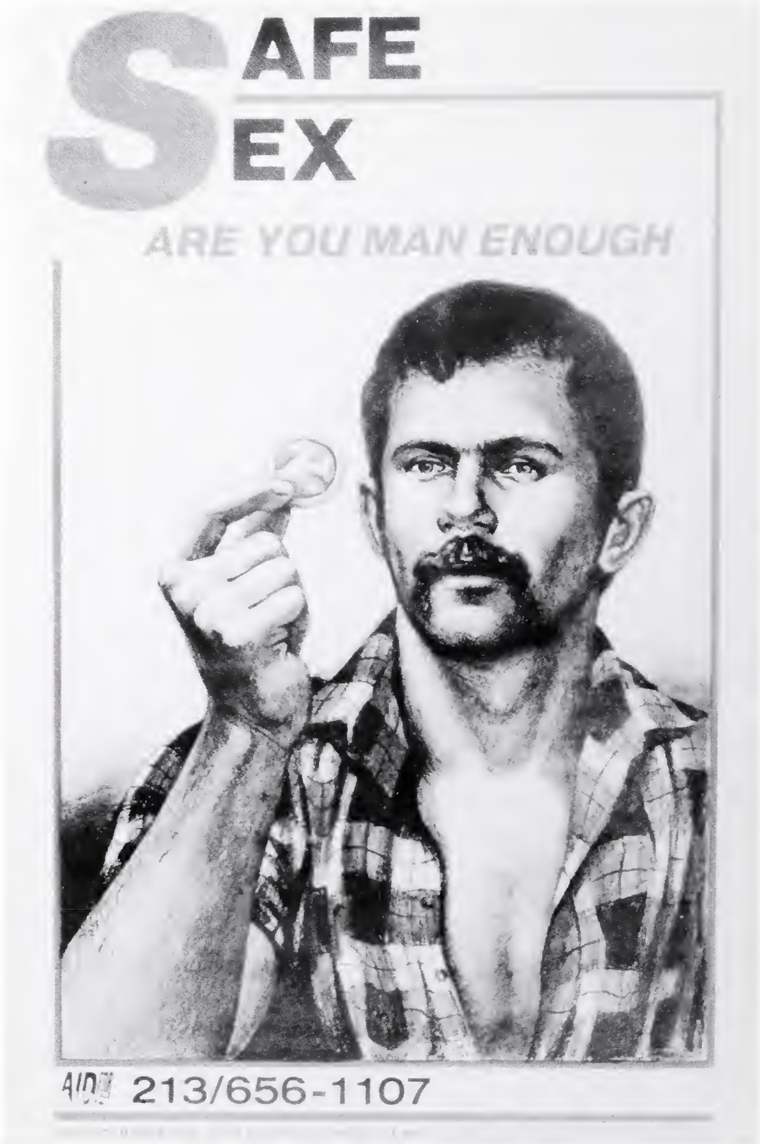


Fig. 10. Safe Sex. Are You Man Enough? One poster in a series distributed to homosexual groups by the California Department of Health to encourage safe sex practices. (Reproduced with permission of Aid for AIDS, California Department of Health. Courtesy of the National Library of Medicine Collection.)

Fig. 11. Mit Gebrauchten Nie! A German poster warning against shared needles in a campaign to "Stop AIDS." (Courtesy of the National Library of Medicine Collection.)

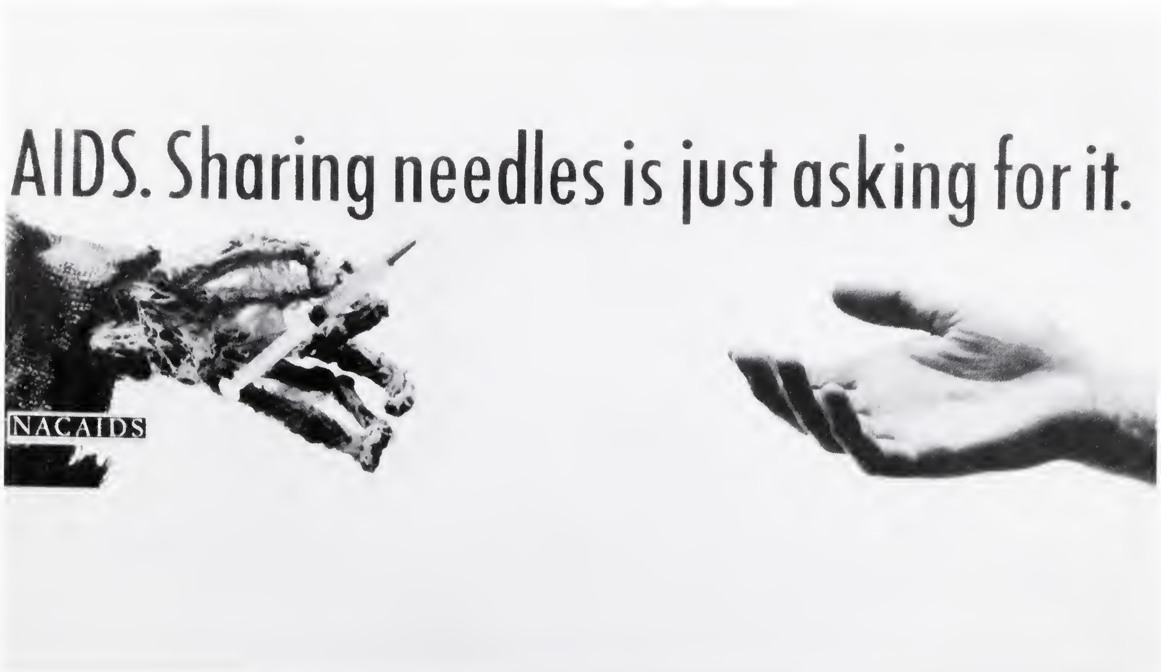


Fig. 12. Sharing Needles Is Just Asking For It. A billboard-size poster published by the U.S. Public Health Service. (Courtesy of the National Library of Medicine Collection.)

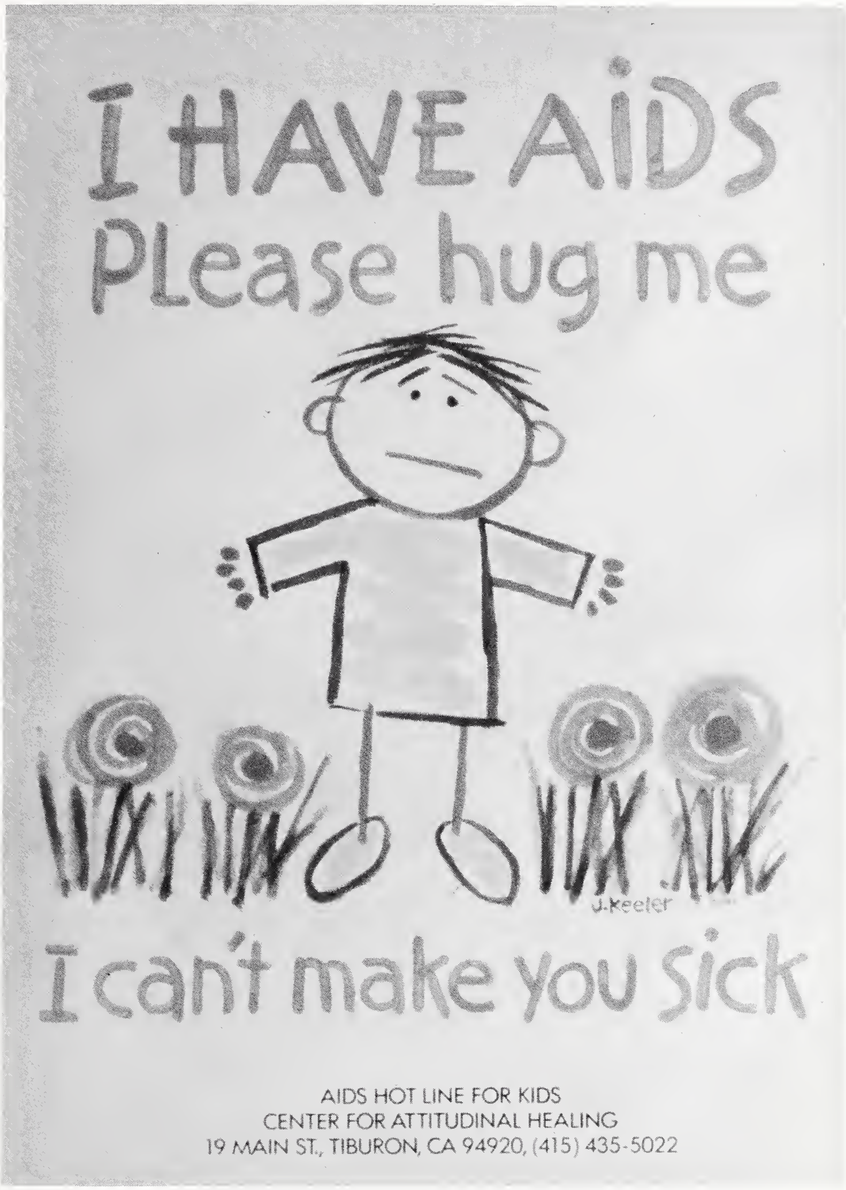


Fig. 13. I Have AIDS. Please Hug Me. Beginning in 1987, posters have been published urging compassion for both adult and young patients with AIDS. (Reproduced with permission of the Center for Attitudinal Healing. Courtesy of the National Library of Medicine Collection.)

Workshop 3

The Response of Government and Society to AIDS

Introduction

Daniel Fox and Elizabeth Fee are the editors of *AIDS: The Burdens of History*, recently published by the University of California Press. Dr. Fee is an Associate Professor in the Department of Health Policy and Management, School of Hygiene and Public Health, at the Johns Hopkins University. Dr. Fox was on the faculty of the State University of New York, Stony Brook; since the conference was held, he has become president of the Milbank Memorial Fund.

James Harvey Young is the Charles Howard Candler Professor (emeritus) of American Social History at Emory University.

Virginia Berridge is Associate Director of the AIDS Social History Unit at the London School of Hygiene and Tropical Medicine.

Paul Kawata is Executive Director of the National AIDS Network.

Suzanne White, historian of the U.S. Food and Drug Administration, provides the commentary.

The Contemporary Historiography of AIDS

**Daniel M. Fox, Ph.D. and
Elizabeth Fee, Ph.D.**

We want to talk critically, but optimistically, about the study of the HIV epidemic as contemporary history. We will first make several points about the historiography of AIDS to date. Then we will discuss the contribution that professional historians can make to the study of AIDS as contemporary history, which, we will argue, is a separate branch of general history linked in special and important ways to the work of our colleagues in the social sciences and the policy professions.

In the first years of the epidemic, AIDS was presented in both formal and informal history as a discontinuity with the recent past, a sharp, sudden return to the years of epidemic disease. Historians have frequently argued that this strange, unexpected outbreak of a virulent infection was like past epidemics of bubonic plague or cholera or yellow fever. The history of AIDS was a history of plagues.

Many policy makers have insisted that AIDS is different, a new kind of problem, and that AIDS defies our ability to come up with solutions. On the other hand, they claim that research on AIDS has produced a triumph for biomedical science. The leaders of the most vocal community groups speaking on behalf of persons with AIDS—the homosexual leaders—have seen AIDS as a setback in the achievements made in the past 15 or 20 years toward liberation from ostracism and stigma. AIDS was thus discontinuous with the perceived direction of recent history.

We suggest that the argument that AIDS is to be understood on the plague model has been used to justify two competing interpretations of how we should use history to examine public policies. One is the interpretation of the alarmists: "This is terrible. The country is being devastated. It will get worse." The other is the interpretation of the advocates of equanimity:

"Even Europe recovered from the Black Death of the 14th century."

It has generally been agreed upon in the historiographic literature to approach AIDS on the basis of the plague model—the plague is at the gates; the city is beleaguered; we must mobilize; we must respond—and yet we know that the plague will go away. That model of history is reflected in the policies of all Western European countries and the United States. The model requires reaching back to the classic tools of public health, the classic notions of surveillance, the classic notions of epidemic containment as modified through the 20th century.

Interestingly, what has been ignored are historical models of chronic disease, which we have only recently recognized as being highly relevant to the experience of AIDS. Dr. Musto's paper reminds us of the importance of tuberculosis as a historical model; yet most discussions of venereal disease and tuberculosis, as they apply to AIDS, have emphasized surveillance measures, personal control measures, and how effective they were, rather than managing and financing long-term care, the problem of long-term public values, and public education. These are the AIDS policy questions we now face, and these are the problems of chronic disease.

AIDS has been primarily presented by historians as discontinuous with the past. Yet the data increasingly suggest that AIDS is not discontinuous with the past, but rather that it is becoming another killer chronic disease, another competitor for scarce resources, another large, organizational, scientific, financial problem confronting the mobilization of health services in the United States and abroad.

The shift from a model of discontinuity to a historical experience of continuity sets the agenda for the doing of contemporary history. The discontinuity model itself provides data for contemporary history. Why did we pick this model? Why did we emphasize it? Contemporary historiography is a troubled and a not well understood branch of the discipline.

Historians have mainly written contemporary history since the days of the ancient Greeks, with the curious exception of the late 19th and early 20th centuries, when many of our colleagues became embarrassed about writing about our own times. Perhaps as a result, much of the best contemporary history of this epidemic has been done not by historians, but by colleagues in adjacent disciplines. The most thorough analysis of the responses of public health officials and homosexual community leaders was written by a political scientist. Other political scientists have written about the response of the media. An economist has published the only history to date of the effectiveness of educational measures. Two policy analysts analyzed the history of perceptions of the cost of treatment for AIDS. A sociologist synthesized the history of the responses of philanthropic foundations; another examined the history of outreach to intravenous drug users. Epidemiologists have told us the most about the origins and the spread of infection; physicians, the most about clinical trials; ethicists, the most about moral dilemmas. A sociolinguist has written extensively about the history of women and HIV infection. Lawyers have contributed important histories of personal control measures, discrimination, and the problem of public health statutes governing the classification of diseases and surveillance. Policy analysts have written the only systematic comparative history of policy for AIDS in Western countries. This is hardly a record of which we historians should be proud; yet it is a record which we should build on, not build fences around.

What can professional contemporary historians contribute to augment the marvelous secondary literature that is developing? It is important to remember that history was basic to most of the social sciences and all of the policy professions until World War II. Although some of our colleagues may be disconnected from professional historiography, their training has been influenced by history, which for two centuries was a basic science for all these disciplines. We believe that history ought to become a basic science again.

Although we share methods, outlook, and interpretive models, there is a fundamental difference between what contemporary historians do and what many of our colleagues in adjacent disciplines do. The major difference is that historians look to the past for questions, not for evidence to support conclusions already reached. History has been a basic science, and we hope it will again become one because history has for a long time been a question-setting discipline. Unless you look to the past for questions, you may use the past only as a source of advocacy.

In summation, there are three issues of theory and method that we bring to our colleagues in adjacent disciplines and in the policy professions, three issues we commend to them and would like to share with them. The first is the theory of social construction. Historiographers can argue for hours about the nuances of the theory, but the fundamental notion is that the definition of disease is negotiated over time by real people in real settings, and that the work of biologists is part of that negotiation.

Second, we bring skepticism about progress. We bring hard-won lessons that it is not easy to talk about improving the human condition. It is not easy to stand back and say "we are better than...because...." There are times when you calculate certain advances. The glory of theorists and methodologists in this fundamental discipline called history is that we can analyze; we can stand back and listen for what one of my great teachers called "the wee small voice that whispers 'Fiddlesticks.'"

The third issue is presentism. We are wary about reading the past backwards, just as we should be wary about reading analogies to the past forward. We need to cultivate detachment and objectivity, even though we know from 2,500 years of historiography that it may be impossible. The struggle is what counts. The historiography of AIDS should be comparative. It should not only be informed by the aforementioned issues, but should also be approached prospectively at least for the next few years, as the history of war has traditionally been approached.

Combat historians offer a useful example of how we ought to examine the complicated human response to AIDS. Those of us who aspire to combat historian status should understand that we should undertake our history reciprocally with our colleagues in other social sciences and in the policy professions.

Discussion

Participant: I wouldn't dismiss the alarmist view so quickly, even with the hindsight of 1989 and new data that AIDS seems to be shifting from an acute to a chronic illness. Perceptions of AIDS as a "plague at the gates" depend largely on the perspective of discrete communities. If the community facing the plague is the entire U.S. population, it was alarmist to see a plague at the gates in 1983–84. From the vantage point of an urban community of homosexual men, however, where a third are seropositive and two-thirds might not become seropositive, if the right things could be done quickly enough, indeed, the plague was at the gates. Such communities believed that many of the traditional programs of public health, such as getting information out and making clean needles widely available, would certainly have saved lives. The "plague at the gates" experience for such a community from 1982 to 1986 was a very real experience.

Speaker: We did not intend to imply that the sense of urgency and threat was in any way unjustified. We were trying to trace a shift in the nature of the social response. Society has moved beyond the idea of plague in an effort to manage what may be an even worse, long-term problem.

Participant: But the people who have to bear the burden have changed. The population of AIDS patients now filling hospitals is a burden for society. A few years ago the burden was faced by a subgroup.

Speaker: Absolutely.

Participant: I could take the position that it is too early for historians to work anyway. When history was the basic science, it did all of the things that everybody else is doing now. In recent years, other groups have spun off—the policy makers, the sociologists, the social anthropologists. They are doing the contemporary history. Historians need to reflect, gather the data, and think. The historian uses a different methodology from people who have taken over the study of contemporary events.

Participant: History is still the mother discipline. Not only have other disciplines emerged from it, but, as other disciplines come up with insights in methodologies, history reincorporates those and employs them with great skill.

Speaker: History is not an autonomous discipline; it shares a lot with other disciplines. At the same time, there is something unique to historians in the ideal of detachment. In my studies of syphilis, historians became locked into ideological perspectives in dealing with the campaigns because of military metaphors that came from World War I. I am a humanist, and I will use the tools of humanism and the tools of humanistic social science to address myself to humane conditions. I think history is written by individuals who have a capacity for synthesizing, and we should fulfill our obligations as people of knowledge and deal with contemporary issues while being wary of military metaphors.

AIDS and Deceptive Therapies

James Harvey Young, Ph.D.

With AIDS, as always, the crime of quackery has been made to fit the punishment wrought by the epidemic. AIDS first appeared in the guise of one of its opportunistic cancers. As scientists explored, AIDS's more basic nature became gradually revealed, its long latency, its apparently inevitable progression through several stages to ultimate death, its routes of transmission, its grounding in impaired immunity, its viral cause. Medical science offered no immediate cure, and palliatives have been few and, to the afflicted, suspiciously slow in coming. This "utterly novel disease" became "a kind of Pandora's box"—I am using phrases from various observers—releasing "dark, primal areas of fear," "our reptilian legacy." As during the early popularizing of the germ theory, citizens dreaded a viral ubiquity. There followed, Susan Sontag noted, "Fear of the Communion cup, fear of surgery, fear of contaminated blood, whether Christ's or your neighbor's."

The public mood was compared to that of the survivors of Hiroshima. In Sontag's words, AIDS is deemed "premodern," as "not only repulsive and retributive but collectively invasive." AIDS contradicts the prevailing interpretation of medical history "as an age-old military campaign now nearing its final phase leading to victory."

Thus, there have been various dimensions of concern to which the unscrupulous could pander: the panic produced by the diagnosis of fully developed AIDS, or by the appearance of the preliminary stage designated AIDS-related complex, or by detection of antibodies in the blood. There was also dread among the undiagnosed, yet awareness of hazard because of the nature of their sexual experience, their drug habits, their blood transfusion history. There was further the broad public's fear of a villainous virus loose and ready to pounce.

AIDS appeared in a social climate that fostered hostility to orthodox medicine and high tolerance for alternative approaches to health care. A San Franciscan stated, "I've never felt that MD stood for 'model of deity.'" An antiregulatory spirit was also abroad in the political realm. In the early 1980's, fighting quackery did not hold as high a priority at the Food and Drug Administration (FDA) as in the 1960's. The word "unproven" did not wave a red warning flag to desperate patients.

The pattern of developing AIDS fraud proved difficult to categorize. It was protean, complex. Dr. John Renner, a quack-buster from Kansas City, tabulated over 300 varieties. No national organization, like the American Cancer Society with respect to unproven cancer therapy, sought systematically to offer a critique of unproven AIDS treatments.

One of the first reactions to AIDS was the way promoters of questionable cancer therapies merely expanded their claims to encompass AIDS, especially in the centers that had migrated into Mexico and the Caribbean. Dr. Lawrence Burton's immuno-augmentative therapy center in the Bahamas, for example, began to use its blood serum to treat AIDs. With sad irony, it was later demonstrated that the serum itself contained antibodies to the HIV virus.

As the viral destruction of immunity became known, safeguarding and restoring immunity became the central doctrines of unorthodox therapy. The health food industry latched on to this approach. Vitamins, especially megadoses of C, a variety of herbs, garlic and ginseng among them, were touted to boost immunity. When Dr. Renner sent students to health food stores in Kansas City asking if they sold things that would ward off AIDS, 15 of 16 managers answered yes. Colostrum from cows, special lights, acupuncture, guided imagery, a bed containing low-amperage coils, all have been promoted for enhancing immunity. A clinic in Berkeley offered to do it with a routine of bathing, breathing, stretching exercises, wearing clothes devoid of synthetic fibers, eating organically grown vegetables, and drinking up to three gallons of ionized water a day.

Other ways of warding off AIDS danger included products trafficking on nonoxynol-9, a spermicide approved by FDA that the Centers for Disease Control (CDC) had found lethal to the HIV virus *in vitro*. Promoters vended creams and condom lubricants, unduly claiming *in vivo* efficacy.

The broader public's fear that the rampant virus would contaminate, as one promoter put it, "public toilet seats, telephones, doorknobs, sinks, tables, and furniture," led to air-purifying gadgetry, antiseptics, a plastic shield for public telephone mouthpieces. The fearful could also lose money on fake diagnostic schemes, like mail order blood testing or hair analysis.

For patients truly diagnosed with AIDS the lure of clinics posed a great temptation, mainly outside the borders. A Coral Gables concern announced a regimen at its clinic in Haiti combining diet reformation, intravenous vitamins, implantation of cells from unborn donor animals, and rectal administration of ozone. At a Mexican clinic, ozone entered by another route. Blood was withdrawn, saturated with ozone, then transfused. Besides ozone, vitamins, and cells from fetal animals, a list of other materials injected into the body to counter AIDS includes amino acids, lily bulbs, hydrogen peroxide, pond scum, snake venom, and the patient's own filtered urine. This appalling parenteral list represents the extremes of therapeutic barbarism to which people with AIDS were in their desperation drawn.

There came to be less drastic, perhaps more hopeful, alternatives. Nancy Pelosi, a congresswoman from San Francisco, made the point at a House subcommittee hearing a year ago while conversing with Frank Young, Commissioner of FDA. "It's a wide spectrum," Pelosi said, "between something that is approved as a drug by the FDA"—as so far only AZT had been fully approved—and, at the opposite extreme, "apricot seeds ground up" (a reference to disproven laetrile). "There are," Pelosi insisted, "some things in the middle that deserve attention."

The drugs in the middle formed the foundation on which rested the growing AIDS underground with its network of "guerrilla clinics." Leaders in the AIDS community in cities on both coasts, angry at the Federal health establishment for not discovering and approving effective drugs more quickly, recognizing the fraud and futility of treatments on the quackish fringe, and oppressed by the hopelessness of facing imminent death without weapons to ward it off, found drugs in the middle in which they sought to place trust. These varied widely, although most had a shred of claim for hope they might be useful, and most were taken seriously enough by AIDS scientists that these drugs went into clinical trials.

Those that most entranced the AIDS underground included HPA-23, ribavirin, suramin, isoprinosine, AL-721, dextran sulfate, and aerosolized pentamidine. Each has its own intricate and intriguing history, with its fate of rejection, acceptance, or, as of now for most of them, continuing uncertainty.

FDA is the final arbiter of the admission of new drugs to the marketplace, and there has been constant battling between that agency and the AIDS community about this middle range of drugs. People with AIDS have used harsh words, one lawsuit at least, and civil disobedience. FDA, yielding to these and other pressures, has accelerated the drug approval process and has relaxed its rules on patients' bringing in from abroad, even importing by mail, small quantities of unproven medications for their own use. Fraudulent and dangerous products, however, are supposed to be barred at the border.

Sympathetic with the plight of people with AIDS, FDA has not sought to interfere either with the use of unproven remedies within the United States. However, as commercialization of falsely promoted AIDS products has burgeoned, FDA has expanded its efforts to combat them. Inasmuch as unprincipled schemes to deceive have always outrun regulatory pursuit, AIDS quackery seems destined to continue.

Notes

Key sources for this report include news releases, talk papers, and other information provided by the U.S. Food and Drug Administration, and coverage in its publication, *FDA Consumer*. Explaining FDA's changing policies is Frank E. Young, et al., "The FDA's New Procedure for the Use of Investigational New Drugs in Treatment," *JAMA* 259 (1988), 259-62. Also useful were FDA's audiovisual tape excerpting lectures at the National Health Fraud Conference in Kansas City, March 1988, entitled *AIDS and Health Fraud*; Randy Shilts, *And the Band Played On* (New York, 1987); *Therapeutic Drugs for AIDS*, Hearing before a Subcommittee of the Committee on Government Operations, House of Representatives, 100th Congress, 2d session, April 28 and 29, 1988; and an AIDS issue of the *New England Journal of Public Policy* 4 (Winter/Spring 1988). Journalistic attention to AIDS fraud also proved of value, including the *MacNeil/Lehrer Newshour*, PBS, Nov. 6, 1985; Scott Ticer, "'Fast-Buck' Artists Are Making a Killing on AIDS," *Business Week*, Dec. 2, 1985; Judy Foreman, "AIDS Patients

Finding Their Own Treatments," *Boston Globe*, May 14, 1987; Janny Scott and Lynn Simross, "AIDS: Underground Options," *Los Angles Times*, Aug. 16, 1987; Katherine Bishop, "Authorities Act Against AIDS 'Cures,'" *New York Times*, Aug. 30, 1987; John Wallace and Cathy Sears, "What Price Hope?" *American Health*, Nov. 1987; Eric Adler, "Fighting Health Fraud," *Kansas City Star*, Mar. 13, 1988; William Robbins, "Doctors Call for Campaign to Reduce AIDS Quackery," *New York Times*, Mar. 16, 1988; Susan Okie, "AIDS Sufferers Buying Hope," *Washington Post*, Apr. 3, 1988; Susan Sontag, "AIDS and Its Metaphors," *New York Review of Books*, Oct. 27, 1988; Joshua Hammer, "Inside the Illegal AIDS Drug Trade," *Newsweek*, Aug. 7, 1989. An expanded, updated, documented version of this paper will be included in the author's *American Health Quackery: Collected Essays*, to be published in 1992 by Princeton University Press.

Discussion

Participant: The licensed drug for AIDS is a purified derivative of herring sperm. When AZT was originally produced, people were being told that herring sperm were good for people with AIDS. Do you think that is quackery? I think we need to ask ourselves what it is that makes us think that something works and something else does not. As soon as AZT was licensed, people started offering it as a sort of panacea for anybody who was HIV-infected. Then it was believed that, in people who are asymptomatic, it could do more harm than good by undermining its own usefulness if they got sicker.

In 1983 or 1984, before we discovered the virus and people were trying treatments, there was some evidence that people on macrobiotic diets did better than people who were not. We can imagine what the reasons might be—a better state of mind, a better feeling about their health. But we would say, thinking about it rationally, that this is quackery. Macrobiotic diets have nothing to do with HIV.

We need to look deeper at how we define what quackery is versus what legitimate medication is, and we need to do it not only from the point of view of rational medical science, but also from the point of view of patients who are seeking to make very difficult choices when physicians cannot give them advice based on experience or definitive findings.

Speaker: I am not arguing that all of the middle drugs were quackery. Of course, the aerosol version of pentamidine has been proved to be useful. HPA-23, which is the drug Rock Hudson went to France to get, quickly proved to be more poisonous than effective. Suramin is another that quickly proved to be poisonous. The hottest middle drug lately, dextran sulfate, may have been demonstrated to be not nearly so useful as it was hoped it might be. Many of these middle drugs are unproven. They require testing, until rejected or accepted, by the kinds of tests that science does use in passing muster by FDA, because the way a patient feels and reacts, the anecdotal evidence, hasn't passed muster with modern science.

Participant: On the other hand, we need to look at the limitations of clinical trials. For example, we believe that a double-blind trial is really double-blind, but in fact most of them are not. It is very difficult to monitor patient compliance.

Speaker: I understand that. I understand that the big community trial in New York that is trying AZT with seropositive patients who have not yet developed symptoms is not enlisting the patients because they are skeptical of the government. It is a failure as a trial, partly because people on it are cheating by using other things and partly because they will not enroll because they do not want the risk of receiving a placebo instead of the drug. Elsewhere in the country, this condition is not so true.

Participant: It seems to me that this is a dramatic reversal in the prerogative of who decides what are we going to study. The laetrile case demonstrated an interesting thing, in that the scientific establishment was forced to grapple with what it believed from the very beginning was an unconventional and inappropriate treatment. A lot of trouble stems from who is setting the agenda about what we ought to be studying and on what basis should we study it. The rational scientific establishment identifies a drug it believes to be promising. But other people also have suggestions and beliefs about alternative drugs. That seems to cause tremendous tension.

Speaker: The scientific establishment did not really believe that there was much hope that alternative drugs would prove efficacious, but, because of pressure from people with AIDS, they performed studies. I think dextran sulfate was an example of that.

Participant: You also raise the issue of the history of the self-help movement and, as one example, the women's health movement, which has been an attempt to take control over one's own destiny in response to medical models which are also social conceptions. I believe that young people faced with life-threatening illness have a sense of time that is probably far different from that of people who can sit back and experiment slowly through different kinds of protocols. Even the approved drugs have side effects. There are all kinds of problems with education about the drugs, about what a medication is and is not. This has been reflected in the desperate search for one medication or one treatment that will prolong life.

Speaker: There are conflicting perspectives. Scientists see us as nearing dawn, amazed at how advances that have taken place in the last 10 years have permitted so much about AIDS to be discovered so quickly. This allows considerable optimism about the long-range prospects for vaccines and drugs for treating AIDS. In contrast, people with AIDS are nearing midnight, deeming therapeutic progress almost nonexistent. There is a wide intellectual and emotional gulf between the two camps, and this helps explain the bitterness that has marked these last years.

Participant: I think it would be interesting to look at some part of the history of faith in medication—what kinds of education consumers have had—and to sift this into the concept of how we go about redefining the fads and fashions of treatment—drugs, experiments, diets—and the tragic response some people are facing.

Participant: Another interesting suggestion of quackery lies in the industry that has emerged to help seronegative people stay seronegative. Clubs are organized around seropositivity or seronegativity, so that members will know one another's status. To me that is an aspect of quackery—selling the idea that such groups can enable you to control your risk for this disease.

The Social History of the Impact of AIDS in the United Kingdom

Virginia Berridge, Ph.D.

This paper describes briefly the overall work of the AIDS Social History Unit and the main themes of the prime research study we are doing. The AIDS Social History Unit, situated at the London School of Hygiene in its Department of Public Health and Policy, is funded by the Northfield Provincial Hospitals Trust, a charitable trust. The original 5-year funding may be extended for another 5 years, so it is funded on quite a long-term basis.

Its work focuses on four specific areas: (1) the study of the development of AIDS policies in the United Kingdom; (2) a study of the historical context of AIDS policy; (3) the creation of an AIDS archive; and (4) the running of seminars and conferences for researchers and policy makers and production of a series of publications. To do all of this, there is a staff of three—a medical sociologist, Phillip Strong; myself, a historian with previous work in the area of drugs and British drug policy; and a secretary. Our main research focus is the study of the formation and the implementation of U.K. AIDS policies.

We are interested not in specific research to solve particular policy problems, but rather in more academic policy research, looking at the particular social, cultural, economic, and historical issues which have actually gone to form policy. We look at policy in a "360-degree perspective." That is, we look at the central government policy, but also at the role of the pharmaceutical industry. We look at the role of the insurance industry and the actuarial profession and at the relationships between those institutions and those constituencies within society.

I should say a word about methodology and how the study is being conducted. We have been working only for the last few months, and have spent those months talking to a range of people from different areas that have been affected by, or have had some impact on, AIDS. So our material comes primarily from an oral study, but we also plan to use a range of published materials, newspapers, committee reports, and annual reports of organizations. But because we are conducting a contemporary history study, oral interviews will play a large part. We hope also to have access to unpublished materials, such as the government's Expert Advisory Group on AIDS.

How can the AIDS story in the U.K. be characterized in terms of trajectory and chronology? AIDS policies to date demonstrate the process by which the institutions of society adapt to an external threat. The early phase of policy development—roughly the period from 1981 to early 1986—can be characterized as policy development from below, and here one can see the influence of volunteer groups (particularly homosexual groups like the Terence Higgins Trust), the construction of clinical and scientific expertise among a group of doctors and clinicians who had not been much involved in the policy process.

During 1986–87, AIDS became a clear political priority. Sections of society were put on almost a wartime footing. This period saw the formation of a cabinet committee on AIDS, chaired by Lord Whitelaw. The media campaign was upgraded into one which had no equivalent since World War II. The British Broadcasting Company (BBC) and Independent Television (ITV) joined together in a committee which was chaired by the government's chief medical officer. This committee took information from the government in much the way one would during wartime.

That wartime emergency period, I would argue, has been succeeded by a phase in policy reactions to the disease have become normalized, in which a new group of professionals have arrived on the scene, and in which some of the original policy experts have become marginal to policy development.

What themes, apart from chronological themes, will run through our research? Our primary concern is to look at AIDS not just from an AIDS perspective, but to relate its impact to more general themes in health and social policy formation. A number of studies have already been done on AIDS and the development of public policy. The work of Daniel Fox, Patricia Day, and Rudolf Kline sees AIDS in terms of a model of consensus policy making. A study by Ian Ferley of policy making in a particular health district talks about the formation of policy from below. These assessments and other theories of policy formation need detailed empirical examination. We need to examine the interaction between particular departments, between professional groups, between the bureaucracy and pressure groups. We need to determine how these policy constituencies have shifted over time and what their impact has been.

The impression we have is of an initial policy vacuum within government—a vacuum in which the policy agendas of outside groups could have influence. One senior civil servant whom we interviewed termed it an example of the danger of lobbies in policy making. Another senior commission member who worked in genitourinary medicine (not noted for its high status or access to the policy arena) noted that he had been readily admitted to the policy arena, that he received regular requests from the Department of Health to give advice, and that his advice was actually transmitted very quickly into policy.

A second theme is that of continuity and change in public policy. AIDS, like war, has intersected in a striking and immediate fashion with the institutions of British society, but the precise nature of that impact needs examination. Has AIDS in fact brought about radical change, or has it been a means whereby societal goals already inherent in existing policies have been achieved. One example here is the question of harm minimization and drug policy. Harm minimization existed as a policy objective for drugs before the advent of AIDS, but AIDS has made it a respectable political concern, as well as a concern for bureaucrats and researchers. That is another instance of the general theme of continuity and change.

This brings us to the historical context of policies. Here, one has to recognize that AIDS intersects centrally with the history of 20th-century medicine, disease, and health policy. We need a historical context, not just in terms of historical parallels or sexually transmitted diseases, but also in terms of research policy, science specialties, drug policy, and public health policy in general.

AIDS policies also need to be looked at in the context of the new public health, because in many respects the emphasis on the role of the voluntary sector—the focus on prevention, on epidemiology, on the economics of health care—has embodied key elements of the new public health of the 1970's and 1980's. AIDS can be seen as part of a pattern whereby over the last two decades the dominance of chronic noninfectious diseases has been challenged by the rise of communicable diseases. We need to set it in the context of Legionnaires' disease, hepatitis B, the recent rise in *Salmonella* and *Listeria* infections, and the rise in sexually transmitted diseases. It is interesting that reports on the public health function published last year were discussed in the Department of Health, which is chaired by Sir Donald Atchinson, the chief medical officer, at the same time that he was deeply involved in management of the AIDS epidemic, and that AIDS was a key policy issue in the Department also.

The interconnection of AIDS and public health and the redefinition of public health through AIDS need examination. There are many other issues: for example, the role of expert groups in policy formation and questions of "ownership" of AIDS. AIDS has engendered professional tensions over who should have prime control over treatment and services. Should it be genitourinary medicine specialists, immunologists, or drug specialists?

A key issue, too, is the question of research policy and AIDS. For example, the Medical Research Council's (MRC) directed program on AIDS is an example of an integrated and proactive research program which is different from the usual science research model in the U.K. There is the relationship between research and policy, exemplified by the evaluation of needle exchange in Britain. There is the role of new research brokering organizations, like the AIDS Policy Unit, formed to bring research and policy makers closer together. There is the enhanced role for social scientists which AIDS appears to have brought. Finally, within research policy, there is the developing relationship between commercial forms of research and basic scientific research, which again is exemplified by the MRC's directed program.

Another important area is the role of prevention policy and the role of health education. There is also the local dimension of national policies, because policy formation at the local level is a key component of the discussion of AIDS policy and its implementation. In the early years, local policies were important in stimulating national attention. For example, the appointment by Oxford City Council of an AIDS Liaison Officer, and the officer's relationship with health services and other local authority services, is an important case study of the way in which policy can be a bottom-up process as well as a top-down one.

Finally, there is the international dimension of national policies. U.K. policy has interacted with policy formation at the international level in a number of ways. The role of the World Health Organization (WHO) and Britain's relationship with its Global Programme on AIDS and the impact of WHO officials on U.K. policy need to be studied. So, too, does the impact of AIDS in Africa on British AIDS policy, the very clear impact that African AIDS made in stimulating the period of "wartime" emergency. International issues need to be brought in to the study of national policy as well.

In this study, we are definitely not in the business of personalization or of apportioning blame. In a review of Randy Shilts' book, the historian Roy Porter argued, "Shilts typically reduces complex issues to personalities and neglects the social structure. By all means, let's blame Reagan and media homophobia, but let us also see that the slowness and ineptitude of the U.S. response to AIDS arose out of the mixed blessings of the decentralized state and of city hall caucus politics." [1]

In the U.K. context, the response to AIDS arose out of the centralized state and interdepartmental battles, as well as local authority politics, but certainly I think the framework of our analysis is the same.

Note

1. Roy Porter. Review of Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic*. *New Society*, 1988 83(1314):24-25.

Discussion

Participant: I wondered if you could tell me your views about needle exchange programs in Britain. What is being done? What are prevalent views?

Speaker: Needle exchange has gone through a number of stages. A report from one of the advisory councils on AIDS and the misuse of drugs was strongly in favor of needle exchange programs. The government response at that stage, however, was equivocal, and only a small amount of money was provided for their development. Since then, the final report of the evaluation study has been published. It was also equivocal about needle exchange programs, saying that they do not attract very young drug users, that people tend to come once but do not return, that they do not stick with needle exchange schemes, and that the evidence of behavior change is not clear.

Nevertheless, I think needle exchange is something that the Drug Section of the Department of Health wants. Many other changes are also occurring in drug policy, especially in expansion of treatment services. The British Government has just given several million pounds to expanding treatment services, and has shifted toward prescribing methadone again. There had been a move away from that during the previous 10 years.

Participant: Is that change in response to AIDS?

Speaker: Yes.

Participant: Would you comment on the view within the homosexual community in Britain of the government's response to AIDS? At the end of your presentation, you seemed to suggest that at least a part of the public believed the response of the British Government to have been slow. It is interesting that in the United States, the response of the British Government has often been held up as a model of what the U.S. Government should have done.

Speaker: I did not intend to suggest that the response of the British government was slow. In Britain, the homosexual community was admitted to a position of policy influence quite early in the epidemic, with homosexuals on the expert advisory group on AIDS, and with the government relying on the Terence Higgins Trust as a source of advice and dissemination of health education. It is interesting how that position has changed. One gets the impression that the homosexual policy constituency no longer has ready access to government. In fact, the government has half-funded a new trust, the National AIDS Trust, which is seen by some homosexual groups as a body designed to control them and to exclude them from policy making.

Participant: If a new trust is being set up and is, in fact, designed to exclude the homosexual groups, there must be reasons. Could you talk about those reasons?

Speaker: I think it is part of the process of the normalization of AIDS, and likewise the normalization of policy responses to AIDS. One can perhaps also link the change to the particular role that the voluntary sector has played, not just in this epidemic, but also in health policy in general in the 1970's and 1980's. The voluntary sector became a key constituency in shaping health policy, but it was a different sort of voluntary sector, one that was primarily funded by the state and linked to the state very closely.

Community-Based Response to AIDS

Paul Kawata

I am not a historian. I do not have the historian's perspective. I am not detached. I am in the woods. I have the passion and commitment of my own belief and that of my colleagues, and we do not see things as clearly, as objectively, as do the historians. I hurt deeply from what this epidemic is doing. I hurt deeply from what it has done to the communities that I work with.

At the same time, I hope to give you a balanced picture. A lot of warts can be seen when we talk about communities responding to this epidemic. Oftentimes, the picture is not pleasant; it is difficult to look at. I think that is the reality of this epidemic called AIDS.

There is no tactful way to say this, but I feel I must emphasize that I have a very different perspective about the government's response to the AIDS epidemic. In hearing people talk about the Centers for Disease Control (CDC), the National Institutes of Health (NIH), and related agencies, it is difficult for me to believe the very cheery picture that is painted. I do not see that same picture. There are some incredible individuals in government who are doing the work. I cannot thank Dr. C. Everett Koop enough for what he has done. I cannot thank Dr. Gary Noble enough for what he has done. The truth is, however, that the AIDS epidemic is not rosy from my perspective.

The National AIDS Network represents 650 community-based AIDS service providers across the country. The diversity of its membership is reflected in the diversity of this epidemic. The majority of initial members came from organizations in the gay community, such as the Gay Men's Health Crisis (GMHC) in New York City, the San Francisco AIDS Foundation, and the AIDS Project in Los Angeles. These were the first communities stricken by this epidemic, and they developed their response because of a lack of government response and a lack of a community response. They have built institutions. When you talk about the "normalization" of AIDS, I think of the GMHC, and it is frightening to me. GMHC began in 1981 with six volunteers in Larry Kramer's bedroom. It now has a budget of $11 million and a staff of 120 people who provide services to those people affected with AIDS in New York City, and yet it still cannot meet the challenge.

Two significant reports permit us to analyze the effect of the community-based response to AIDS. The first is *Confronting AIDS*, a report by the National Academy of Sciences (NAS), which talks about the unique and important contribution of targeted community-based education. It talks about peer-to-peer education and the value of that system. It talks about the value of having communities speak for themselves, whether it be gay people talking to other gay people, black people talking to other black people, or Hispanics talking to other Hispanic people. A second report, put out by the President's Commission on HIV Infection, talks about the value of the community-based response. Specifically, it notes the fact that the community-based response came before the local or the Federal Government response. It actually enabled the government to create and formulate policy.

An unpublished paper that I co-authored describes community-based AIDS services[1] and the different types of responses that are happening across the country. One group I always like to talk about is the People With AIDS Coalition in Dallas, TX. This coalition has put together a 38-unit apartment building in which people with AIDS provide housing for other people with AIDS. Since the paper was written, the coalition has bought two additional buildings with money from the Health Resources and Services Administration (HRSA) to establish two residences, one for families with AIDS and another for IV drug users with AIDS.

We are talking about people taking care of themselves. Belle Glade, FL, is one of the most incredible places I have ever been in the United States. Walter Cronkite did a special show, "Harvest of Shame," about this town. I took the Ambassador to Sweden to Belle Glade because Swedes did not believe U.S. information about how AIDS was and was not transmitted. We went to Belle Glade to talk about mosquitoes. In Belle Glade, there is no running water, no sewers, no phones, and no electricity. This community has raw sewage on the streets, so there are numerous bugs and mosquitoes. Three nuns take care of a town in which there was at one point the highest per-capita incidence of AIDS in the world. When I met with these nuns, I truly felt what it meant to be with spiritual people. I asked them, "Why do you do this? How can you do this without resources, without the commitment of your local government?" They turned to me and said, "We do this because we have to do it, because there is no one else to take care of these people, because these are people that other people don't care about."

My experience is that there are people like this all across the country. They are the heroes in this epidemic. They are the people on the front lines, the people who change the bedpans, who cook the food, who take care of the dying, and it is not easy. The greatest challenge that they have is to learn how not to cry, because if they took the time to cry every time somebody in their lives died, they would not have time to do their work. It is a difficult challenge.

The other critical component to community-based organizations is education. Education happens at the community level. Baltimore's Earth-Tide Program, for example, hires IV drug users and former IV drug users to go into shooting galleries to talk to IV drug users. Another program, in Washington, DC, at the Whitman-Walker Clinic, hires former prostitutes to talk to working prostitutes about use of condoms and IV drug use. This unique form of peer-to-peer education can only happen at the community level.

Community education includes the series, developed by the GMHC, of controversially explicit comic books to educate gay men about ways to protect themselves against HIV transmission. They were very explicit in explaining to gay men about how to put on a condom, how to use a condom. But according to the NAS, this is the most effective way to reach those populations. Community-based education is exactly that: reaching hard-to-reach and difficult populations.

These organizations face numerous problems. I am very proud of these programs, but that does not mean that there are not problems, incredible difficulties. For example, Houston, TX, has the fourth largest case load of AIDS in America, yet the community-based organization there receives less than $6,000 in government funding. They have only two case management workers, who currently provide services to an active case load of more than 700 clients.

I was in Houston training the case management workers, and it became apparent to me that they had to create innovative mechanisms in order to handle such large case loads. They established a self-diagnosis case management system, which absolutely is not working. I must be blunt about this. It is not working in Texas. They have very little money, and restrictive laws and policies are being developed. It is a bleak picture.

Another agency facing particular problems is the Shanti Project in San Francisco. For the past 3 or 4 years, it has been held up as a model of community-based service in this country. In 1987, Shanti provided 189,000 volunteer hours to people with AIDS in the community of San Francisco. But this organization is experiencing the professionalization of its leadership, a transformation that many other community-based organizations have faced. Such change produces conflict when the old leadership lacks the skills, the ability, or the willingness to let go and carry the organization to new levels. At the Shanti Project, it produced a vicious public battle over the control, direction, leadership, and vision of the organization.

It is not just the Shanti Project that is affected by professionalization of the organization. That kind of change produces conflict in all organizations doing this work. It is something we all must consider as we move toward the normalization of this epidemic. We walk a fine line, and there are no simple ways to reconcile the passion and commitment of the original grassroots volunteers with the needed professionalization of the organizations. The conflict is even more painful because the work performed is not easy. It is the most difficult work I have ever done; it is harder than anything I ever thought I would do or would have to do in my entire life. What is required to stay in this work is a passion, a commitment, a fire from within.

As we go to larger and more professional organizations, we have to figure out how to balance that fire and that passion with professionalism, and there is no clear answer. I encourage historians to take the time, to allow themselves the luxury of time that they do have, but that I don't have, to evaluate the changes in community-based organizations. Where does their experience fit in history? What lessons can we learn? The lessons that I have learned over the last 3 years change month to month, week to week, day to day. The bottom line for me and for all of the organizations with which I work is compassion, providing a response for people who were shunned and turned away by the majority of society. It is a bottom line of bringing together Hispanics and blacks and gays in ways that they have never before been brought together. It is a bottom line of caring, and of burying people we love.

Note

1. Paul Akio Kawata and John-Manuel Andriote. "The National AIDS Network—Promoting Community-Based AIDS Services." Unpublished manuscript. See also idem, "NAN—A National Voice for Community-Based Services to Persons with AIDS." *Public Health Reports* 103 (1988):299–304.

Discussion

Participant: What is being done to preserve the record of this incredible effort that you describe?

Speaker: Not enough. We have an internal clearinghouse that keeps brochures, pamphlets, and other information on all of the organizations. We are also starting an oral history archives at GMHC, because it was the first organization. There are amazing stories to be told, but when your resources force a choice between providing care for someone who is sick and creating an archive, the choice is clear.

Participant: You are right to point out the organizational stresses of growth and dealing with funding issues. Other problems of organizational development have to do with racism and sexism. It has been difficult for white homosexual male organizations to deal with black and Hispanic communities, and it has also been difficult for white homosexual men to work with women. Those problems have been prevalent in many AIDS service organizations, and I think we really have to examine how those accommodations have been made, or not made, in different places, and why.

Speaker: That may be the toughest issue we face in terms of delivery of services. Homophobia exists in minority communities. Some traditional black and Hispanic health organizations are unwilling to provide services to black and Hispanic gay men. Some white gay communities are unwilling to provide services to gay men of color and to women.

Before AIDS, we had racism and sexism and homophobia. Even after AIDS is overcome, we will probably still have racism, sexism, and homophobia. AIDS tends to magnify all of the problems of our society. It holds up the magnifying glass to all the weaknesses in the fabric, but AIDS also forces us to work on these weaknesses in ways we have never before had to.

Participant: To what extent has the constituency of the National AIDS Network changed as AIDS has moved more and more into the inner cities?

Speaker: It has changed drastically. The best reflection of our constituency is on the board of the organization. When we first started, the board was five people: four gay men and one straight woman. After our last election for the executive committee, four of the five members were black. This reveals the drastic shift in the face of the epidemic. Of the four who are black, three are women, and one is a person with AIDS. Within minority communities, AIDS is also an issue of poverty. You cannot deal with AIDS in the black and Hispanic communities without dealing with poverty.

Participant: Do your community-based organizations have a lot of problems with the religious right? In Columbus, Ohio, the few churches that are trying to help the homosexual community organize have come under attack.

Speaker: My experience with churches is the same as my experience with other people during an epidemic—you see the best and the worst of people. You see some of the most compassionate responses coming from churches, and you also see some of the most vicious attacks coming from them. There is no one answer. It varies from community to community. A priest on my board reflects the incredible, compassionate movement generated within Catholic Family Services in New Orleans. Other Catholic churches have been less compassionate.

Participant: What effect will the professionalization of community-based AIDS organizations have on responsiveness to community needs?

Speaker: Initially, efforts of community-based organizations to hire professional executive directors have met with failure. The reason is that the position is not a nice, 60-hour-a-week job. It is very difficult. Even if community-based organizations can pay their executive directors salaries of $100,000 to $150,000 (and many are), the demands of the job are overwhelming for many professional people. For people who have not experienced an all-consuming job that becomes your life, it is difficult to step into that role.

Participant: Could you talk a bit about the positive effects of these organizations in education and prevention and how you are able to measure these effects?

Speaker: To measure the effectiveness of education and prevention, you have to have money and sophistication. Many groups with which I work do not have the money or the sophistication. We have made some measurements, mainly in the San Francisco white gay male community. To measure the effectiveness of education programs, we looked at the reduction of rectal gonorrhea rates, which roughly translate into reduction of HIV transmission. We think that this shows the effectiveness of the education programs, because just 3 or 4 years ago, public health educators would never have anticipated the rate of reduction we have achieved, especially in light of the serious increase in sexually transmitted diseases among heterosexuals in most major U.S. metropolitan areas.

Commentary

Suzanne White

This challenging group of papers defies simple summation. The authors were all grappling in one way or another with the idea of assessing the nation's response to the AIDS epidemic. Has it been adequate or inadequate, timely or not timely enough? What were the constraints on both individual and collective responses? How did our response differ from, and how was it similar to, that of other nations confronted with the same disease? Finally, are we historians in a position to make accurate historical observations and judgments given the currency of the disease?

Naturally, the homosexual community itself responded immediately to the needs of its stricken members, but as Mr. Kawata makes clear, this community felt that the efforts of Federal outsiders were both untimely and inadequate. He tells a tale of communal triumph in the midst of personal tragedy, and his questioning of the adequacy of governmental responses to the crisis in the homosexual community gives us reason to pause. The key here is the perception of having been reached. Mr. Kawata's assessment, which he challenges us to question and document, is that the homosexual community did not feel that it was reached in a timely or compassionate fashion in the midst of the AIDS epidemic.

Dr. Young draws our attention to the governmental response of one particular Federal agency, the Food and Drug Administration (FDA). This agency, he points out, has found it difficult to shape a compassionate response in the midst of this epidemic. In its attempts to protect sick people from products and promoters making false representations about the efficacy of their products for AIDS, and in its commitment to test drugs carefully and thoroughly for safety and efficacy, the agency found itself charged with ignoring the needs of dying people in its quest for scientific integrity against the AIDS virus. As the agency struggled to safeguard the blood supply, approve AIDS test kits, and test gloves and condoms to make sure that they could protect against the spread of the virus, it came under increasing attack for ignoring what Congresswoman Pelosi perceptively termed "the drugs in the middle." Drugs that seemed a long shot to scientists were seized upon as a small ray of hope for desperate patients. The luxury of time, so taken for granted by scientists as a hallmark of modern drug regulation and an important safeguard against misuse of drugs, suddenly seemed a cruel and unusual punishment to those exposed to the AIDS virus and their advocates, and the FDA was forced to reassess its own role in getting drugs onto the market in order to meet the challenge of the deadly disease.

The writings of Dr. Fox, Dr. Fee, Dr. Young, and Dr. Berridge serve as excellent examples of the kind of research and writing on current issues that historians are doing and doing well. Increasingly, historians such as Dr. Berridge are being called upon to submit studies that can influence policy makers. Dr. Berridge has brought not only an international perspective to the history of the AIDS epidemic, but also a keen appreciation of the uses to which that history may be currently employed. If historians synthesize the known material well and are aware of the limitations of their own studies, if they employ historical skepticism, then the question of historians writing current history is reduced to manageable proportions. The papers presented in this session provide ample evidence that writing history in the topsoil is neither wasted nor futile.

Workshop 3
Summary of Small Group Discussions

Social historians should examine the response to AIDS in areas usually neglected by other writers. Most writing to date has examined the major urban centers which have had a high incidence of AIDS and of political activity relating to AIDS. What about state and local responses outside these major cities? How have rural areas dealt with AIDS?

Educational efforts to alter health beliefs and practices should be examined. An analysis of the state of health education would set in context recommendations for specific educational activities related to AIDS. The roles played by physicians, other health-care personnel, and community-based groups should be included.

Historians should examine the history of AIDS drugs trials within the larger administrative history of drug testing in different countries. What role has AIDS played in changing drug testing protocols? What ethical questions have been raised in testing AIDS drugs? How reliable are the scientific results from the altered protocols? What role has been played by gray-market drugs.

The contextual net for studying the history of AIDS policies may need to be broadened. Policy studies in isolation will be inadequate. To explain the relationship between African AIDS and British AIDS, for example, the larger history of British policies toward Africa must be investigated. If volunteer groups have played a significant role in developing AIDS policies, a historical perspective on the relationships of voluntary bodies with the state is needed to provide context. Comparative studies are also needed, such as analyses of AIDS policies in different countries and studies of the effectiveness of AIDS voluntary organizations as compared with other voluntary lobbying groups in the past.

Historians should examine their work in relation to the formation of public policy. There is some debate over whether historians should seek to influence the formation and implementation of public policies. Those who advocate active involvement believe that historical publishing needs to investigate more effective techniques of dissemination to broad public audiences.

Workshop 4
Documenting AIDS History: Preserving the Records of the Scientific, Institutional, and Popular Response to a New Disease

Introduction

Dr. Harden: The following papers draw together issues raised in earlier workshops, focusing on the nuts and bolts of documenting the history of AIDS. The suggestion has already been made that a national AIDS archive be established. We discussed this issue at the formative meeting of the AIDS History Group; very quickly we realized that no single repository could possibly hold all the information that is being generated. Centralization of the AIDS documentation would probably not even be desirable. Decentralized collecting, however, raises the possibility that no one will adequately document this disease. Whose responsibility is it? This is a key question that we must address, along with its corollary: "Who will fund the process?" Other issues include the future disposition of collections now maintained by voluntary agencies that may disband, the role of government, and the documentation of artifacts relating to AIDS.

The authors of the following paper are grappling with these issues. Peter Hirtle is the curator of modern manuscripts in the History of Medicine Division, National Library of Medicine. Ramunas Kondratas is a curator in the Medical Sciences Division, National Museum of American History, Smithsonian Institution. Nancy Zinn serves as librarian for special collections at the University of California, San Francisco. John Parascandola, the commentator, is the Chief of the History of Medicine Division, National Library of Medicine.

Documentation in the Federal Government for the History of AIDS

Peter B. Hirtle, M.A., M.L.S.

As a librarian and archivist as well as a historian, I was pleased that the organizers of this conference decided to include a workshop on documenting the history of AIDS. Good history is in large part a product of good sources; without adequate documentation, knowledge of even the most cataclysmic events can be lost. Of course, historians traditionally have been very effective in using the smallest threads of evidence to recover the story of the past. As we learned from Dr. Risse, historians have been writing successfully about the history of epidemics for several hundred years now, in spite of the absence of much specific documentation on disease. Dr. Musto pointed out that we can write about the history of tuberculosis in spite of the fact that in the 19th century no group of historians sat down and discussed how to document tuberculosis. Historians may actually be at their best when they are forced to take whatever records are available in an archive or library, no matter how few in number or seemingly irrelevant to the investigation, and then to squeeze as much meaning from the documents as possible. Historians' skill is the reason that we have excellent histories of, for example, plague in Renaissance Florence in spite of the fact that contemporaries made no conscious decision to produce or collect records specifically to document the spread of plague. Yet, as a general rule, the more available the documentation, the broader and more complete the history.

Some might argue that the problem we face today is that there is too much information on AIDS spread across too many agencies. As Dr. Schechter reminded us, by 1989 there were more than 4,000 publications on AIDS, with more than 2,000 just on virology. Pity the poor graduate student, who Dr. Harden suggests should work on the history of virology, who must sit down and read 2,000 papers to understand just 1 year of developments in the field. It very well could be that future historians of AIDS may have too much information rather than a paucity of it. In addition, the mere quantity of information about AIDS generated each year does not guarantee that the records of most interest to historians will be preserved.

I cannot do anything about the extent of the documentation of the AIDS crisis. I have, however, developed a personal interest in the Federal response to AIDS and am knowledgable about how Federal archival and recordkeeping practices work. I can therefore discuss where material might be located and how it can be approached. Whether the records of the AIDS epidemic will continue to be available for the use of future historians is a question I would like to leave you with, while suggesting some actions you, as active historians of AIDS, can take to ensure that useful material is available for your successors.

How does one begin to locate the sources for the history of the Federal Government's response to the AIDS crisis? A good place is with the printed literature, both monographic and journal. From the first published report of AIDS in the Centers for Disease Control's (CDC) *Morbidity and Mortality Weekly Report* to the mailing on AIDS sent by the Surgeon General to every household in America, the government has been actively publishing expressions of its knowledge about AIDS. A variety of tools are available for searching this literature, including AIDSLINE®, which is available through the National Library of Medicine (NLM).

Unlike librarians, however, historians normally mean unpublished primary sources when they think of "documentation." AIDS documentation is no different from any other Federal activity, and it is approached in the same way. To locate the unpublished records in the Federal Government of the AIDS epidemic, one must first ask where and how the Federal Government is involved with AIDS. The records of Federal funding of outside individuals and agencies involved in AIDS research, for example, are found in part in the National Institutes of Health (NIH) records, because NIH is a major source of extramural AIDS research dollars. There may also be information in the records of the Food and Drug Administration (FDA), however, or the CDC. Historical investigations of NIH in the 1950's have shown that even the records of the Bureau of the Budget can be an important source of information for NIH history, as the Bureau was involved in the development and approval of new programs. I imagine the records of the Office of Management and Budget (OMB) will be a similar rich treasure trove for historians of AIDS.

With AIDS, the Federal Government's response has been broad and far-reaching. There are, therefore, myriad places to look for records relating to AIDS. Previous sessions at this meeting have concentrated on the response of the Department of Health and Human Services (DHHS). Let us not forget that almost every cabinet-level agency in the government has most likely had some contact with the AIDS epidemic. AIDS discrimination and its regulation would be of interest to the Department of Justice (DOJ). The Immigration and Naturalization Service within DOJ, in conjunction with the State Department, has to manage the entry of people with AIDS into the country. The OMB has to worry about the cost of AIDS programs and whether, for example, CDC is going to get the money it needs for AIDS-related activities. Other agencies in the government may wish to establish personnel policies about AIDS among their own workers. Historians interested in the Federal response to AIDS, therefore, will need to cast their documentary nets very broadly before the entire story can be told.

Of course, DHHS itself has been the government agency most concerned with the AIDS epidemic. Even within this one department, the organizational response to the AIDS crisis has been extremely complex. The Secretary of DHHS is the focal point and final arbiter of the Department's approach to AIDS, but in this action has been assisted by the Assistant Secretary for Health. The Office of the Assistant Secretary for Health has directed the DHHS response to AIDS, but there is also within DHHS a National AIDS Program Office. The Public Health Service (PHS) is the component of DHHS that is perhaps most responsible for implementing the Department's response to AIDS. Former Surgeon General Koop, as we all know, established policies which will be of interest to future historians. Most of the research related to AIDS is being done by CDC, NIH, and the Alcohol, Drug Abuse, and Mental Health Administration, but FDA and the Health Resources and Services Administration also contribute to PHS's response to the AIDS crisis.

Within each of these agencies, organizational subunits have responsibility for different policy areas. At CDC, for example, seven different components contribute to CDC's AIDS work. At NIH, the National Cancer Institute, National Heart, Lung and Blood Institute, and National Institute of Allergy and Infectious Diseases have been in the forefront in research, but almost every NIH Institute sponsors research on AIDS. There is also an AIDS Program Office within the Office of the NIH Director, and the Director of NIH also has general policies to direct all this activity.

It is important for historians to understand the structure of the government's response to the AIDS crisis in order to identify the source of records of interest. For example, a sloppy future journalist or historian, when faced with this complexity, might simply turn to the records of the Surgeon General's Office and assume that the story of the PHS's response to AIDS is found there. Certainly, a part of the story will be found there, and Dr. Koop's role in the history of AIDS cannot be discounted, but a historian who assumes the records of AIDS will someday be found in Dr. Koop's papers at the National Archives may be sorely disappointed. Much of the correspondence, memoranda, reports, and other documentation about AIDS signed by the Surgeon General or sent to him for approval are generated in other offices. The official copy of these records, even when signed by the Surgeon General, is found not in the Office of the Surgeon General, but in the records of the agency that created the document. A common refrain I have heard from historians interested in the actions of the modern Surgeons General is how little of interest there is in their office papers.

To understand fully the records of the PHS's response to AIDS in the 1980's, therefore, one will need to look at the records of the subsidiary offices, agencies, departments, and divisions. Similarly, there is no single Federal Government whose records on AIDS can be easily identified and used. The government is not monolithic. It is myriad agencies, each of which has its own activities, functions, and recordkeeping policies. The neophyte AIDS researcher, therefore, needs first to identify what agencies addressed a particular problem of interest, then try to locate those records.

Because of the size and complexity of the Federal Government's response to the AIDS crisis, information officers, official historians, and librarians can play an invaluable role in helping outsiders understand both the function and activities of the admittedly often arcane Federal bureaucracy. Government historians in particular can be valuable allies, for they understand both the administrative environment in which they work and the documentation needs of historians. In addition to helping researchers understand the Federal bureaucracy and identifying the likely location of papers of interest, government historians also work to ensure that those records are saved from eventual destruction. In those Federal agencies which have historians, one of the historians' duties usually is to work with the National Archives appraisal staff to ensure that records of permanent historical value find their way to the Archives. If there were more official historians in the Federal Government, therefore, there would be a better chance that the government's records relating to AIDS would be preserved.

DHHS has not had many active historical offices in the past, but there are indications that this is changing. The FDA has an active and growing historical program, and NIH has established a historical office and museum. There has been some discussion of establishing a similar office in PHS. These are developments which all historians should applaud and support.

Not every agency can afford to have its own historical office. As a consequence, much of the historical work performed in the government is done by historians who are under contract with an agency to produce discrete historical products. A good written history prepared by a contract historian can provide the same sort of background information and local knowledge that a government historian can provide in person. Furthermore, agency-sponsored institutional history, whether it is done by an agency historian or a contract historian, tends to favor description of organizational and administrative functioning over analysis, exactly the sort of information a historian needs as he or she seeks to unravel the complexity of any Federal response to a crisis. On the negative side, contracts are usually let for specific historical projects and for a limited period of time. Once the project is completed, the contract ceases and the connection between the historian and the agency is severed. The historian under contract is under no further obligation to help either the agency or historians interested in learning more about the agency's activities. And, with the passage of time, contract historians' knowledge of the agency that they had studied would decrease, limiting their potential usefulness as a source of knowledge about the agency for other historians. It is unclear, therefore, whether future historians will be able to use contract historians as continuing sources of information, much as they would use official historians. Still, any knowledge about an agency, whether gleaned from in-house government historians or from histories produced under contract, can be valuable to the neophyte researcher in Federal history.

Just as government historians seek to identify and preserve records of permanent historical value, so too contract historians have contributed to the retention of records, though usually not in the National Archives. There are, for example, collections in NLM which were compiled by contract historians as part of an assignment to write a history of a governmental agency. These sometimes include records which the historians removed from PHS office files and which they then added to their own research files. In many cases, the PHS office files were never offered to the National Archives, but were instead destroyed. If the contract historian had not removed the records now found in their research files, these records too would have been destroyed and be lost forever to future researchers. It would be best if the National Archives' record retention schedules worked so that all Federal records of permanent historical value made it to the Archives, but in the absence of such a situation, the efforts of contract (and official) historians to identify and preserve key documentation may be the next best thing.

The researcher's first task is to identify which agencies are likely to have generated records of interest. In this task, the researcher may be assisted by government historians, published histories, information officers, and librarians. The next step is to locate the records. This leads the researcher into the areas of records management and records retention, and to the National Archives and the Federal Records Centers. To understand where the Federal records of the AIDS epidemic may be located, it is first necessary to understand how the government manages its records, and how it identifies those of likely permanent value.

In spite of the Paperwork Reduction Act and other efforts to cut down on the size of government records, the Federal Government is awash in paper. More recently, electronic records have been added to the total. Most of these records document mundane matters, such as travel orders, routine personnel decisions, and acquisition of supplies, which are of little permanent historical interest. The National Archives estimates that the material documenting development of the government's policies and procedures (material that would be of future historical interest) comprises only 2 to 3 percent of all the paperwork produced by the government. The task, therefore, is how to dispose efficiently of the 97 to 98 percent of the records that are not of historical interest, while preserving in the National Archives that small percentage that is of interest.

To meet this challenge, the National Archives developed the principle of records management. They have identified many kinds of records found in the government and have determined for how long these records need to be retained. The document that specifies what kinds of records exist in an agency and the retention period for those series is known as a "retention schedule." Requests for building maintenance, for example, might be kept for 3 months, at which time they are destroyed, while files documenting the development of policies, such as the NIH Director's program planning files, would be kept permanently. A whole range of retention periods exists between these two extremes.

At some point, records may no longer be of immediate use to the government, but still are not immediately disposable. It would be expensive and inefficient to store these records in agency files. The National Archives, therefore, has established a series of Federal Records Centers for agency records. Any Federal agency may transfer inactive records to the Federal Records Center for storage. When the retention period for the records expires, the records center destroys them. If the records are deemed of permanent value, the agency can, after an appropriate period of time (often 20 to 30 years), offer the material to the National Archives. Until this material is transferred to the Archives, however, the records remain under the custody of the agency which created the records, even though they may be in a records center run by the National Archives. A researcher interested in examining these records needs the permission of the agency to consult the records.

In principle, the records management system in the Federal government is a good one, but in practice it has its limitations. Some are structural. Records management as a discipline grew out of the needs of the Archives in the 1940's to deal with records from agencies such as the Department of Defense which tend to be heavily hierarchic and bureaucratic. In such organizations it is possible to preserve only the records of the top administrators and still document fully the development of policy, because most matters of importance cross their desks. This is not a good records retention model for decentralized agencies such as the NIH or CDC, where decision making and research most often are localized.

Disagreement over what kind of material is of permanent historical interest has also arisen. At NIH, for example, the record schedule stipulates that the files of Institute Directors and Advisory Committees are among those to be saved, but that the case files of funded and unfunded grants do not need to be saved. One could not, therefore, track individual grant-funded research projects from their initial conception through their finished form. Most troubling to many is that in most cases the records of intramural research at NIH are not scheduled for permanent retention. Such records are to be discarded whenever the Laboratory Chief decides they are no longer of scientific use or if they are not of use in establishing patents. If, for example, someone at NIH were to find a "magic bullet" that cures AIDS, the records of the research leading up to the development of the cure would not automatically be scheduled for permanent retention; their preservation would be dependent upon their future scientific value to the laboratory in which the work was done. Fortunately, at NIH this could never happen. The NIH Historian would make sure that the records were offered to the National Archives as a special case. There may be other breakthroughs at NIH, however, which while still of historical interest would not come to the attention of the NIH Historian, and these records are therefore likely to be lost.

Assuming that material of interest has found its way to the Federal Records Center (and for the AIDS crisis, most material that is no longer with the agency will be found in the records center), how does a historian identify and gain access to the material? Each agency's records officer maintains records of what has been sent to the records center and can arrange to have material made available to a historian. Depending on the agency, requests can be made directly to the records officer or first to the agency's Freedom of Information Act coordinator. In most cases, the reference archivist at the National Archives can direct requestors to the proper person.

Historians who gain access to material at the records center can play a vital role in preserving key AIDS documentation. If you find records that in your opinion will be of value and that are not scheduled for permanent retention, let the head of records appraisal at the records center, the reference archivist for that records group, Dr. Harden, or me know, and we will do all we can to see that the material is reappraised and preserved. Recently, a historian at the records center found a goldmine of information in the central records of the National Institute of Mental Health. These records were not scheduled for permanent retention, and some of them had already been destroyed. The historian not only mined the material for his own use; he also contacted the proper authorities, and now, thanks to his efforts, that material has been appraised, identified as being of permanent historical value, and offered to the Archives, where it will be better organized, better described, better preserved, and more accessible. As historians of AIDS, you will be using the records in just years, and sometimes months, after they have been created. Please help us identify those of permanent value!

Historians can also help make sure that material makes it to the records center in the first place. Few scientists and administrators at NIH and CDC would, I suspect, recognize that their laboratory notebooks or data files are Federal records subject to the records schedules established by the National Archives. Often, in the eyes of the scientists, their research notes belong to them and can go with them when they leave. In the short run, this attitude has led to the preservation of much scientific research material. Scientists have taken their files and notes with them when they have left NIH, and then either offered the material to the archives at their new home institution or to NLM. If, however, a working preservation program for scientific records were in place at NIH, such an attitude might in the long run actually contribute to the loss of important scientific data. Again, I would urge any of you who are studying developments as they take place in the agencies and laboratories to explain to the key scientists, administrators, and regulators the likely historical interest in their actions, and encourage them to preserve their papers for posterity.

I should not finish with the idea that the prospects for the documentation of the history of AIDS are all bad. One advantage to the contemporaneousness of this crisis is that we can do something about it. We can identify records that need to be preserved or, in some cases, even created. Here, I applaud the Gay Men's Health Crisis in New York for starting a videotaped oral history program with AIDS victims, creating a historical record which would not have existed otherwise. As historians, we have a responsibility to help identify and preserve important documentation for the future, either as individuals assisting the National Archives in the identification of records of permanent historical value, or through a lobbying campaign for the establishment of official NIH and CDC historians, perhaps even for the creation of a separate AIDS historical office.

For the study of past epidemics, historians have had to work with whatever records had survived, often by chance. Because AIDS is a contemporary crisis (really only 8 years old), we can identify now what kind of materials future historians will need for their research, then work with archivists, physicians, and scientists to make sure those records are preserved. The quality of the historical record of the future is dependent on our actions now.

Discussion

Participant: What is the nature of the relationship between the National Archives and Records Administration (NARA) and NLM?

Speaker: The National Archives was created in 1935. Many earlier records left the government and found their way into new homes. Other Federal records are considered by the Archives to be nonarchival, and hence disposable; some of these records have also entered other institutions. I know of no immediate plans by the Archives to try to recover Federal records that may have found a home in another institution. They have more than enough to do with the records still in the agencies.

On the other hand, the Archives does not, in principle, allow Federal agency archives to be established outside of the National Archives, nor can it permit current Federal records to be transferred to NLM. Furthermore, NLM would not want them. Federal records in most cases should be sent to the National Archives. Problems arise mainly when Federal officials refuse to turn over their records to the Archives or, more rarely, when the Archives, because of space, staffing, or access concerns, cannot or will not accession records of recognized historical importance and permanent value.

Participant: Could that be solved by special legislative means? Would it be worth trying?

Speaker: The problem, as I see it, is not at all a question of jurisdiction between Archives and the NLM. Thus, the solution is not legislation. The real problem is how to ensure that important material at NIH, CDC, PHS, and other medical agencies of government is sent, at the appropriate time, to the Federal Records Center. Once important documents are identified and scheduled, they will be offered to the Archives for permanent retention. The system that exists is quite adequate, if it is used.

Participant: How does the collection process work?

Speaker: Let us use the example of NIH to illustrate how the Federal archival system works. Records are identified by the agency as being of historical importance and worth preserving. If the Archives appraisal staff agree with the assessment, the records are scheduled, boxed, and shipped to the Federal Records Center for storage. Normally, they stay at the Federal Records Center for 30 years, at which point they are offered to the National Archives. The Archives evaluates the records once more to determine whether they are indeed of permanent historic value. If judged historically valuable, the records are retained by the Archives. Arrangement of the records is supposed to follow the original arrangement in the agency, and the level and kind of arrangement are products of their original condition, likely use, and available staff resources. Unfortunately, many records arrive at the Records Center without identification, schedules, or preliminary appraisal information. This material can take years, if not decades, to evaluate, and still longer to process. Federal records judged not to be of historical value to the government may be offered to other non-Federal libraries and archives, though in most cases the information is destroyed.

Participant: In the interim 30-year period, are they accessible?

Speaker: They are accessible, but not through the National Archives. Because the records in the Records Centers are still the property of the creating agency, researchers must go through the agencies themselves to gain permission to consult the material. Generally, you must get permission to examine the records from the agency's Freedom of Information Act officer, after which the records officer orders the records retrieved from the Records Center.

Participant: It sometimes seems that the Federal Records Center is becoming more efficient at scheduling records for destruction and that the Archives is becoming slower at appraising records. Furthermore, the volume of work at the Archives seems to be so overwhelming that agency liaisons often can't keep track of inquiries. Is there any hope of improving the system?

Speaker: I am optimistic about the future. The National Archives recently got permission to build a second facility, Archives II, which will be located on the University of Maryland campus. It will be a state-of-the-art archives facility and will greatly increase storage capacity. It has also undertaken a massive project to appraise all unscheduled records in the

Records Center and even in some agencies. The goal is to identify all material which should be moved to the new building, so that the rest can be discarded. This means that a lot of "loose ends" will be resolved during the next 5 years. The remaining problem will be to make sure that historically important material in the agencies continues to be offered to the Archives.

Participant: Are all significant files, such as grant records and progress reports, scheduled for automatic preservation?

Speaker: Not really. Minutes of the scientific review meetings conducted by study sections are scheduled for permanent retention, as are the final results of any grant, but to the best of my knowledge, this is the only material at NIH relating to specific grants destined to be offered to the Archives. Several years ago, the Joint Committee of the Archives on Science and Technology recommended that granting agencies include, as a condition of the grant, the stipulation that grant recipients maintain the grant files, the research records and other products of the grants. It was a wonderful idea that, unfortunately, seems to have gone nowhere. Of course, such a stipulation builds in extra overhead, and someone has to pay for it. Perhaps the recent concern with fraud and plagiarism in grant-funded research will lead the granting agencies to rethink their record retention requirements.

The Artifactual Legacy of AIDS

Ramunas S. Kondratas, Ph.D.

My message and plea are simple: that while we are casting our nets broadly to collect and document the history of AIDS—looking for books, documents, papers, and audiovisuals—we do not forget the three-dimensional artifacts, because they will play an important role in understanding, and particularly in teaching, the history of AIDS. It is not enough, in my opinion, to collect the written records. The actual objects to which many of the printed materials refer—the drugs and therapeutic devices, the diagnostic test kits, the laboratory and safety equipment, and the educational tools—serve several important purposes.

First, they are the material legacy of AIDS to be preserved for future generations. We may not be able to collect everything or even be omniscient in what we should collect, but those of us who have tried to build collections know we can rely on our knowledge and training as historians of medicine to determine the kinds of materials that are important in writing and interpreting the history of medicine. For example, in trying to determine what to collect in the newly exploding area of biotechnology and molecular medicine, I look back at my and others' work in the history of bacteriology of the late 19th century, and I know what I wish had been preserved at that time. That is one guideline in trying to determine what should be preserved now. Others will soon learn about the dearth of biomedical artifacts and the consequences of it. Not much has been preserved. Just as we preserve the written record of disease, we should also preserve the artifactual material record. That is the bottom line.

Preserved artifacts will be used as objects of study and analysis, just as are texts, to show how researchers studied and understood AIDS, how AIDS was treated, and the social and popular dimensions of AIDS. At the National Museum of American History, we have argued a long time among ourselves and with our colleagues about what one can learn from objects themselves that one cannot learn from photographs and other descriptions. I strongly believe that you can learn things from artifacts that you cannot from texts.

We also use objects for teaching, through exhibits that reach a broad segment of the population. Historians of science and medicine can reach a much larger audience through exhibits than they ever could through their publications. It is important for all of us to become involved in exhibit and public education projects.

But you cannot mount good exhibits without the real objects. People come to museums to see the real things, not to see photographs of them. For an exhibit, you need the three-dimensional artifacts in order to attract the public and focus their attention on the issues you want to raise. You have to find these objects somewhere. They have to be preserved by someone.

We cannot wait until the AIDS story plays itself out to decide what to collect. Our experience has been that objects tend to disappear quickly, more quickly than the printed word. There are no comprehensive efforts to preserve artifacts on a par with the efforts of libraries, archives, special collections to preserve the written record. Certainly there are museums, but not many museums are interested in science or medicine. In fact, the number of repositories for scientific and medical artifacts in this country and throughout the world is rather small. This makes it even more imperative for us to see that the important artifacts related to the history of AIDS are collected, preserved, and properly documented.

In documenting AIDS drugs, the history of AZT would be at the top of the agenda. We have collected from Burroughs-Wellcome and the National Cancer Institute, but much more could be done to document the story of AZT. Then there is the large gray area of experimental drugs. They should also be collected, whether or not they be proven efficacious, because they represent the numerous attempts by researchers to find an effective therapeutic agent against AIDS. The third area would be the pseudoscientific or outright quack remedies. They represent the desperate attempts by AIDS patients to prolong their lives and the villainy of those who try to take advantage of them. We have established a nice working relationship with the FDA in trying to find drug samples and preserve them.

Another category of objects is the AIDS test kits, such as the ELISA test and the Western blot test. The largest category is the laboratory equipment used in the study of AIDS. Laboratory instruments will probably disappear quickly because laboratories are changing rapidly as new technologies come into being. Those laboratories working at the forefront, especially on AIDS, cannot take the time to save old equipment. They are likely to junk old equipment and acquire new machines right away.

My experience in collecting biotechnology instrumentation has been that if it is 5 years old or older, it will have been discarded. You might find an old commercial model, but not the prototype or first model. I was lucky to find some of the earliest DNA and protein synthesizers, as well as the prototype DNA sequencer, but this material disappears quickly.

An important instrument for AIDS research is the cell sorter or separator. We were lucky enough to acquire the prototype of a second-generation machine invented in the Genetics Department at Stanford University, then developed commercially by Becton and Dickinson Company. These machines are very important because they can produce homologous cell samples quickly and in large quantities. It was difficult with the old electrophoresis apparatus to separate and sort large quantities of cells from closely related tissues. These machines can sort about 10,000 cells per minute and pick out a tagged fluorescing cell among millions of unmarked ones. They are important instruments for monitoring and studying AIDS.

How should such instruments be collected? You cannot simply pluck an instrument or object out of its context and put it on exhibit or in the museum storeroom. You must also understand and document the contextual history of that machine—who made it; who used it; when; whether or not there are drawings for it; whether or not photographs or other visuals show it in use; whether or not laboratory notebooks describe the work done with it. We can also use oral and video histories to help document the development of these instruments. All of these will become important records for the study of biomedical technologies. In many areas of biomedical research, including AIDS, technological breakthroughs have been the fuel that kept research going and accelerating. If it had not been for the technological breakthroughs and the new instruments, much of the ground-breaking work could not have been done. In order to interpret properly the role of these instruments, it is important to do contextual collecting.

Special attention should be paid to the new safety equipment being developed, primarily in response to AIDS, to protect health workers and researchers from exposure to blood and body fluids. This equipment is "hands-off" technology designed to reduce the risk of accidental needle sticks, such as nonreusable syringes and puncture-resistant containers for their disposal; gloves, gowns, aprons, masks, and face shields; and mechanical pipetting devices, mouthpieces, resuscitation bags, and other ventilation devices to protect against contact with saliva. There are also special urine sample containers, chemical germicides for cleaning laboratory work surfaces, and safety cabinets in which AIDS laboratory research work is done. Other safety equipment no doubt will be developed as we continue to fight this deadly disease.

Another area of collecting is educational devices. I have seen ads for reproductive anatomy models for AIDS education, and condom and foam use demonstrations. There is a cartoon character called Bleach Man, and Bleach Man comic books. A person dressed like Bleach Man, with a mask in the shape of a Clorox® bleach container and a Superman® suit with a big "B" on it, walks the streets of San Francisco promoting safe sex practices and the use of bleach to clean intravenous drug needles. Other comic books, as well as posters and videocassettes, are being used throughout the country to educate young people about AIDS and other sexually transmitted diseases. We should collect a representative sample of these to document the social and educational aspects of AIDS.

There are also the memorial pieces, the memorabilia. The AIDS quilt project is a good example, a graphic and moving memorial to the victims of AIDS. It grows in size daily and travels as an exhibit around the country. Its organizers envision some day a separate museum or storage facility for the whole quilt. That would be a massive undertaking from a financial, storage, and conservation point of view. We have already had discussions in our museum about preserving a few quilt panels and documentary materials.

In addition to the quilt there are diaries, oral tapes, and videotapes of people who have suffered and are suffering with AIDS. They have been produced as a legacy of their lives and deserve to be preserved. No one institution can do this, but it could be done locally throughout the country.

The last collecting category is contraceptive devices. They represent a major effort on the part of the health community to stop the transmission of AIDS through the promotion of safe sex practices. Advertising for condoms and warnings on condom packages are beginning to reflect concern about AIDS and venereal diseases. Institutions have been reluctant, for various reasons, to collect and display objects related to contraception and birth control. But if we want to document fully the history of AIDS and other sexually transmitted diseases, we must overcome this reluctance.

The AIDS History Group can play an important role as coordinator in the collection effort, because some key people in this group work in museums that collect medical artifacts, including AIDS-related materials. It is unfortunate that outside of Washington, with the exception of the Dittrick Museum in Cleveland, and the Mutter Museum in Philadelphia, there are no large medical museums that we know of willing or able to collect in this field, especially on the West Coast. That is a problem all of us should think about. There should be a West Coast repository for this material.

We can develop collecting guidelines and help set collecting priorities. These guidelines could be distributed to museums, historical societies, and other collecting units nationally and internationally through such organizations as the Medical Museum Association, the European Medical Museum Association, the Association of Science and Technology Centers, the Association for State and Local History, the American Museum Association, the International Museum Association, UNESCO, and the World Health Organization (WHO). We should be collecting globally to document the history of AIDS. There are already international AIDS conferences and a World AIDS Day. I have worked successfully with the WHO in collecting materials related to the history of smallpox and its eradication, and I feel confident that it also could be done with AIDS.

Because of lack of storage space, proper storage equipment, and staffs to process very large collections, no one existing institution could become the central repository for AIDS materials. It is imperative for us to see that as many different groups and museums and historical societies as possible become interested in collecting and preserving some of the artifactual legacy of AIDS. These organizations will have to communicate and network among themselves to coordinate collecting activities, avoid duplication, and share resources. We in this group can help by impressing upon our colleagues and other people the importance of preserving material culture, the importance of artifacts for the study and interpretation of history. Some institutions may say they are not interested in science or medicine. But AIDS is much more than that. It is part of the social history of their community and their country. There are many effective arguments and ways to galvanize support, and historians will find and use them. I ask your help in spreading the word so that we can preserve this important legacy.

Discussion

Participant: As president of the Medical Museums Association, I would like to say that we helped organize the AIDS History Group in New Orleans last year. We are trying to connect museums with historians. We hope to publish a directory of the Medical Museum Association, consisting of about 60 individual members representing 38 museums, collections, and archives. I will distribute it to every participant here with the intent that you should encourage interested museums or curators to get involved in collecting AIDS artifacts.

Speaker: I appreciate the problem that no single museum or archive is large enough to hold all the AIDS materials. I wonder, however, whether just encouraging everyone to collect will be sufficient. Some archives would not want this material because they would designate it "medicine and science" and thus outside their collecting area. Perhaps a certain limited number of archives in the country should be designated official AIDS archives. They could publicize their interest so that people would know to send materials to them. As a historian who has run from this archive to that archive to locate material about a single subject, I think coordination would be beneficial.

Participant: The keys are coordination and networking. We are trying to establish a mechanism for doing that. The number of large institutions interested in collecting medical artifacts and that have the staff and storage space to do it is limited. Moreover, such institutions already have large medical collections to care for. They would have to be selective in collecting AIDS-related materials. But they could act as clearinghouses in finding homes for artifacts, knowing who was collecting what around the country, and steering donors to the most appropriate places. They could also give advice about what is important to preserve.

Documenting AIDS: The Role of the University and Other Agencies

Nancy W. Zinn, M.L.S.

The opportunity to identify and preserve the records created by agencies and organizations that deal with the AIDS epidemic is a challenging one. The disparate groups involved with AIDS and AIDS-related complex (ARC) on many levels are creating unknown quantities of material. Throughout this conference have echoed the calls for finding ways today of dealing with these records to ensure their availability tomorrow.

Not long ago, at a Senate hearing before the Subcommittee on Government Efficiency, Don Wilson, the newly appointed Archivist of the United States, spoke about the major responsibility of the National Archives in the "Federal Government's administration of its own records."[1] It also plays a vital role in the determination of a "policy for documenting our national heritage." The National Library of Medicine (NLM) plays a similar role with regard to health-related, nongovernmental records. Nevertheless, the basic work of documenting human ideas and activities becomes the task of smaller groups, which, when the results of their efforts are put together, can provide the resources to paint the broad picture of life in the United States, and in this case specifically, the AIDS epidemic.

In contrast to the passive acquisition of materials which often characterized the process in the past, manuscript and archival agencies are beginning to adopt more aggressive and more broadly defined collecting philosophies. Today's archivists are better educated and trained, and supported by more sophisticated and tested methodologies that enable them to plan and implement these philosophies successfully.

The fields of science (whether medical or physical), once greatly neglected by institutional collectors of records and manuscripts have been attracting more interest. Three efforts exemplify manuscript collecting foci which have emerged in the last decades: (1) the Modern Manuscripts Collection at NLM; (2) collections in medical care, health policy, and social medicine at Yale; and (3) the collections in the Contemporary Medical Archives Center at the Wellcome Institute for the History of Medicine, London. These examples should stimulate other, local efforts, but until we know more about who is creating records and what exists, we cannot be effective in collecting and preserving such records.

Earlier, it would have been impossible to propose collecting on the scale currently contemplated; no single institution had sufficient resources. Now, in response to the major increase in records being created and to technological changes, the archival community is exploring a procedure known as "documentation strategy."

Documentation strategy, which is beginning to be tested throughout the country, attempts to identify and define broad areas (for example, specific topics, industries, and activities) needing documentation for specific locales (e.g., a neighborhood, a city, a township, or a state). Part of the process is devoted to identifying the participants and spelling out the various roles they will play in the discovery, description, and preservation of important records.

The inclusion of the records creators is an important facet of the process. By involving them in the developing stage of the strategy, it is easier to secure their support and compliance. Equally important is the designation of a number of archival or manuscript repositories for the preservation of identified materials. Cooperation of the latter is vital, because such broadly conceived topics incorporate records in numbers that are beyond the capability of any one institution to preserve, even when the process has narrowly outlined records to be saved.

AIDS is a major phenomenon affecting communities throughout the world. Information about who is involved on many levels—political, laboratory research, economic, public health, legal, social services, patients and their loved ones, among others—is crucial to discovering records related to the topic. A concerted effort must be made now in communities across this country, particularly those which were hit the earliest and the hardest, to come to grips with the survival of these records; only then will it be possible to support research in the future.

A wide variety of data in many formats—manuscript, printed, audiovisual, electronic—will have to be surveyed, categorized, cataloged, stored, protected, and made accessible by participants in the process. Each facet of this process needs to be specified and carried out according to a plan adopted by the participants, who must agree on their own roles in the process and their relationships with each other as well.

To document the AIDS epidemic in Community X, how would the process begin? Staffs of a state university or historical society library or archives might convene a meeting of logical participants. Contacts would be made with records-creating individuals and agencies, as well as representatives of universities; historical societies; municipal archival agencies; private, public, and research libraries; and museums in the community or region.

At an initial meeting, after reaching consensus on the need for such a program of record conservation, the group would explore the tentative parameters of the program. In deciding these, the goals, size, space, staffing, funding, expertise, interest, and commitment of each of these entities would help define their functions. In addition to tasks dealing directly with the records themselves, their roles must include responsibility for providing leadership and direction, for administrative support, grant supervision, fund-raising and information and publicity, and staff expertise in specific areas. The cooperative nature of such an interinstitutional activity requires clear elucidation of and agreement on roles.

Initially, the group would discuss the extent of their projected commitment within the context of their own institutional goals. Care and preservation of records, particularly those not currently needed or used, is a minor priority for the records creators. Sensitivity of the records is a major concern. Often, the staffs of community social service groups are short-term volunteers whose energies are focused elsewhere; they would need substantial support to maintain their interest and compliance. Consequently, other institutions would be called on to provide broader, sustained support.

Universities, because they are educational institutions, and by virtue of their long history of support for the gathering and preserving of information, are logical sites and resources for documentation strategy activities. Historians on their faculties could help provide the broad context for documentation, rationale for sampling techniques, and identification of likely participants. Development of classes focused on the AIDS epidemic might elicit response by students willing to participate in limited segments of the documentation process.

Many educational institutions have archivists and manuscript curators experienced in dealing with all types of records, who could help identify record types germane to the subject. Their long association with donors and with acquisition procedures could aid in the development of effective approaches to potential participants. University libraries and archives can also be depositories for selected materials; again, the institution's goals support such activities. The AIDS/ARC-related records generated by faculty and staff would, of course, be scheduled for transfer to their own archives, and might serve as examples of records to be sought in the broader community. The same faculty and staff have connections outside the university, and thus could provide useful conduits to the community for identifying and approaching possible participants in the search for records.

National access to collected materials through many media is an important segment of a documentation plan, for both the collectors and the users. The past 10 years have seen the growth of national on-line cataloging utilities (OCLC and RLIN) which offer access to records of a wide variety of materials across the country. Most university and college libraries are associated with one of these services. Of course, the staff's specific expertise in this area, and in processing records and preparing finding aids, would be the backbone of any documentation program. Expertise might be needed to create a local data base describing the nature and the locations of the records once they have been surveyed; this, too, could be found on university campuses.

University libraries and archives staff might also share information with staffs of other agencies who lack knowledge in the care and housing of such materials. Some state archives also have programs in this area. However, major funds to support the documentation process (including staff for surveying, processing, and supplies) would probably have to come from sources outside the group. Most educational agencies, as grantees, are also a source of information on writing grants and administering awards. They may also be able to support personnel associated with directing and carrying out successful proposals.

Similar skills are available in historical society staffs, and those in state archives. At both the state and local levels, historical societies can offer knowledge of yet another community of supporters and contributors. Each locale would have to explore the feasibility of sharing such expertise.

As many historians have found to their dismay, local city or municipal archives are few compared to state-level and university archives. Where municipalities have no records management or archival programs, departments (such as health and social services) in these locales may have widely differing information on the extent, condition, and availability of their own records. In such cases, a documentation strategy program might successfully cooperate with public health officials to seek out and suggest means of preserving public health records relating to AIDS. It could even stimulate the local government to initiate a records management program.

State archives have a particularly important role to play in identifying and saving documentation of AIDS-related political and legislative activities at the state level. They can provide valuable information on legislators' interests and the legislative processes, which may be relevant to funding state activities. State archives staff are also an invaluable source of information and expertise for the National Historic Publications and Records Commission (NHPRC) grant proposals, which are submitted through state review boards, and which are logical sources of practical support for documentation strategy activities.

Presumably, the records of state government departments associated with AIDS/ARC have already been scheduled for preservation. If they are willing and able, state archives also can contribute significantly to the coordination of documentation activities across the state. They might act as a clearinghouse, through which information can be distributed about documentation strategy groups focusing on AIDS in different locales.

Of all the groups that might participate in an AIDS documentation strategy, the one that could be problematic is the commercial or business interest. Pharmaceutical or biotechnology firms may be unwilling to make their records relevant to AIDS available to researchers for a variety of good reasons. The absence of such records will represent a major gap in the grand picture, however, and commercial firms might be persuaded to make their records available at a future date.

In today's fiscal climate, cooperation and networking have become the buzzwords of library and archival communities. We are always being exhorted to avoid duplication, to find ways to accomplish more while spending less. The documentation strategy process exemplifies one pragmatic approach to this philosophy. It requires the willing participation of all groups before specific steps can be taken to identify types and amounts of records and to agree on policies and procedures to preserve records and make them available. Certain agencies will be responsible for their own records, but some independent community agencies will not be. Therefore, it is the cooperative agreements reached in the document strategy process that will determine how successful we will be in deciding which records should be kept, which repositories will accept which records, how and to what extent the records will be processed, how information about the records will be disseminated, and what will be the guidelines governing future access.

Historians, whose stake in the survival of records is large, are an important part of the process. They need to recognize the necessity for specificity and rationale in record selection. Space grows tighter every day, and even with advances in information technology, only a small portion of available records can be saved.

Archivists and librarians need the support and participation of historians in developing the strategy, in approaching funding offices and agencies, in locating records, and in educating records creators. If ever cooperation was necessary, it is now; the future depends upon the present, and tomorrow's researchers depend on our efforts today on their behalf.

Note

1. Don Wilson. "To Preserve the Human Record." *History News*, 1988 Mar–Apr 43(2): 6.

Commentary

John Parascandola, Ph.D.

The first impression one gets from these papers is that we have too much documentation. I have two examples here from the National Library of Medicine (NLM) that demonstrate the size of the published literature. One is the library's *AIDS Bibliography*, which comes out quarterly. It is simply a bibliography that lists essentially the research and clinical literature. It is not comprehensive. It does not even begin to touch popular literature. One issue consists of 3 months worth of references, numbering thousands of citations. How does one deal with a literature that is so large?

The other example is NLM's AIDSLINE® data base, which consists of AIDS citations, from the library's MEDLINE® data base. It is being expanded to include citations drawn from various other data bases such as HEALTH and BIOETHICSLINE®, in order to incorporate literature on ethical and legal questions surrounding AIDS.

We have too much material, but the fact that there is so much does not necessarily ensure that we will be able to preserve and provide access to these materials for future historians. The materials are dispersed all over, and there is no guarantee that much of this material will survive. We need to consider three things:

1. **Selection.** How do we appraise what needs to be saved? What kind of strategies do we adopt to select material? We obviously cannot save it all.
2. **Preservation.** Who is going to preserve this material? How are we going to preserve it?
3. **Access.** How are we going to get at this material? I doubt that material documenting AIDS will ever be concentrated in just a few places. In fact, we will need to encourage many organizations to do their own preservation, or perhaps to join together for this purpose. Maybe a support organization could be created,

> to which voluntary groups could all contribute, to develop an archive for their materials. In our pluralistic society, there is no easy way to convince different organizations to put their records in one particular repository. And certainly more than just a few agencies will be required to deal with this quantity of material.

It is not feasible for any one institution, not even NLM, to collect and preserve all of the important published and unpublished materials on AIDS. Despite the relatively vast resources of the library, it has traditionally dealt primarily with printed materials; in fact, they are the great strength of the library. NLM collects the scholarly, printed record, and probably holds as complete a record of the scholarly and clinical literature as any place in the world. The holdings are probably as comprehensive as any in the biomedical field. NLM does not, however, collect patient education literature, or general health education literature, except in a very limited way.

It was only about 25 years ago that the Library set up the Modern Manuscripts Collection. This partly reflects changes in the direction of medical history. We know that 20th century medicine is now a hot topic among medical historians, whereas some 30 years ago a majority of the papers in the *Bulletin of the History of Medicine* or on the American Association for the History of Medicine meeting programs were on pre-1800 medicine.

The library's collection of archival, modern manuscript materials does not go back that far. The manuscript staff consists of Peter Hirtle and one full-time technician, plus occasional student assistants. This is a smaller staff than that of the Chesney Archives of the Johns Hopkins Medical Institutions. Peter Hirtle does a tremendous job with the limited staff resources that he has. The library is aware of and concerned about doing more in this area, but Federal resources are scarce these days.

NLM cannot possibly devote inordinate resources to AIDS, as important as we think it is, because as a national library it has an obligation, just as does the Smithsonian as a national museum, to collect in all areas of health. With respect to modern manuscripts, NLM tries to focus on collections of national interest, either the papers of individuals who had a national impact or the papers of organizations that are national in scope. The library has to rely on regional archives to collect materials from their own regions. There is no way around that.

The same kinds of resource limitations apply to the audiovisual collections. NLM has an audiovisual archive and an archivist who is responsible for several thousand historical films, videotapes, and other audiovisuals.

But NLM cannot do it all. It needs to share the responsibility. It needs the help of other agencies. Perhaps the library could provide some of the leadership and possibly some of the funds. It does provide some support for library and archival collections through its extramural funding program. Recently, funds have also been earmarked to assist preservation efforts in other institutions as part of a national preservation plan. These funds are limited, but other organizations, such as the National Endowment for the Humanities, are also providing funds for preservation. And perhaps NLM can also lead efforts to coordinate collecting and to produce guides to the source materials.

Another concern is the ephemeral nature of so much of this material. Much of the documentation, for example, that deals with public education campaigns consists of ephemeral types of materials—comic books, posters, and the like. NLM cannot collect all of this, so it has decided to focus on posters, within its Prints and Photographs Collection. The Smithsonian Institution is also collecting some of this material—ephemeral literature that accompanies artifacts. Many of the artifacts themselves are ephemeral, as well. Finally, the records of community organizations working with people with AIDS are at risk of becoming ephemeral, because these organizations are swamped with work. These organizations are not unaware of the importance of preserving their materials, but it has to take a back seat to saving lives.

There are many problems associated with modern records, not all of them unique to AIDS. The key concerns relate to the need for increased resources and more individual and organizational involvement. I hope that conferences such as this will at least produce increased coordination. Perhaps other institutions will be willing to tackle specific aspects of the problem, such as some of the ephemeral literature.

Summary of General Discussion

Networking between community organizations and local or state archives could help preserve documents that might otherwise be lost. Organizations serving people with AIDS are generating important records but rarely have the resources to devote to archival projects. Local and state archives, however, are logical repositories for such records and artifacts. The American Association of State and Local History (AASLH) could foster documentation of AIDS by generating interest in such networking arrangements among its members.

Other local strategies may help to preserve AIDS materials. Models should be developed to train community organizations in records preservation. If local organizations recognize the importance of their contributions, they are often willing to learn such techniques. Developing exhibits on the response of particular communities to AIDS can provide AIDS education and simultaneously sensitize those communities to documents, artifacts, and oral histories that should be saved. Finding ways to combine intervention and long-range history may be very important in preserving AIDS materials on the local level.

Creative ways must be found around archival storage problems at the local level. The price of renting or buying new storage space for local AIDS archives may be prohibitive. Interested people often house such archives in their basements, but records may be lost if those people move or die, or if they suffer fire or flood. Two possible solutions to this problem are (1) new technologies for storage, such as optical disk systems, and (2) careful selection of key records to minimize volume. In addition, private-sector firms such as pharmaceutical companies may be willing to assist well-planned documentation efforts in conjunction with local archives.

Nonprint media held in private archives can provide rich sources for writing the social history of AIDS. Historians should be aware of newspaper, radio, and television archives that are well indexed and accessible. In addition, several photograph collections, such as the one at the National Museum of American History, Smithsonian Institution, have made a special effort to collect photographs by local artists relating to AIDS.

Private collectors can build important collections relating to AIDS. Many fine collections have been built by private collectors, and some collectors are interested in AIDS. Although such collections are usually skewed to the personal interests of the collector, they may be exceptionally rich in particular areas. Many a collection has survived because one individual scoured the country to build it, exerted great effort to preserve and catalog it, and persevered to find a permanent home for it, occasionally endowing an institutional archive to care for it.

Archives and museums around the world need to collect AIDS materials. To capture the varying responses to AIDS, institutions in each country need to collect documents and artifacts relating to this disease. The AIDS Social History Unit in Britain provides a model for collecting and writing about AIDS with a relatively small staff.

Could we be overdocumenting AIDS to the exclusion of other diseases? Will we leave the historical record warped, implying that AIDS was the most important medical problem of our time? Most conference participants believed that there was little danger of this. Because AIDS is extremely important in our society at this time, it may provide future historians with a case study in how societies react to crises. Diseases that are less publicly visible do not elicit the same response. Furthermore, many materials and objects needed to document AIDS come from diverse disciplines, such as molecular biology and immunology. To provide sufficient context for AIDS, archivists and museum curators will perforce collect materials in related areas.

Closing Remarks

Dr. Risse: This conference grew out of discussions held by the AIDS History Group in New Orleans during the 1988 annual meeting of the American Association for the History of Medicine. The metaphor of AIDS as a magnifying glass was used by many speakers at the conference, and it is an apt way to express the reasons our AIDS History Group got together last year. We believed that AIDS furnished an opportunity to mobilize ourselves, not only to focus on the disease but to discuss historical documentation strategies. We talked about the sensitive way in which we must look at public policy issues and the pitfalls of contemporary history in general, not just of AIDS history.

We have had two intense days of presentations and workshops, during which we have sharpened our skills and our awareness of the social and scientific dimensions of AIDS. We must indeed broaden our conceptual net. We designed this program deliberately to bring together various constituencies. We need to forge a relationship between historians and the AIDS communities. We want from them primary information: the individual impressions, the collective pain and frustration, and the passion to understand and deal with this disease. At the same time, historians have an obligation to give something back to persons with AIDS and their caretakers. It must be a reciprocal relationship. We need AIDS communities to collect materials for us, but we must give something back to them in return.

Historians must exert leadership in initiating studies at the community level, whether they focus solely on AIDS or on other public health problems as well. Historians must not only hold dialogue with representatives of other academic disciplines but must go back to the AIDS communities and offer their insights. The AIDS epidemic is forcing us to rethink our strategies and to open up, to cooperate with AIDS communities. We have to give in order to receive. Historians and members of the AIDS communities must walk together.

Thank you all for participating in this conference. I would especially like to thank Dr. Harden, whose diligence and efforts were largely responsible for making possible this magnificent opportunity for discussion, and her assistant, Joan Shariat, who ably managed the logistics.

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